

# I Chose to Change: Living with Chronic Pain – Stories from Patients

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### **Your choice**

Pain is something unavoidable in our life. But how to face pain varies from person to person. Some pain such as headache and stomach ache can be alleviated through painkillers. However, the chronic pain suffered by some patients will remain even after medication, which greatly affects their psychological health and mood.

With the advent of technology, the health care professionals have better knowledge of pain: from simple medication and interventional therapy to a multidisciplinary team therapy approach that combines the disciplines of psychology, biology and sociology. One such example is the Comprehensive Outpatient Engagement Program (COPE) that is run by the Alice Ho Miu Ling Nethersole Hospital (New Territories East Cluster) Pain Management Centre.

But regardless of the advance in technology and the efforts of the health care professionals, the chronic pain patients still need to work together with family members and the society in this battle against pain, so as to break the vicious cycle of chronic pain and restore confidence for patients. In this way they can overcome challenges on their own with faith and the know-how.

This book documents the experience and struggles of a number of patients. Though they have gone through the shadows of valleys of death, they never give up during tough times. They are willing to receive help from their family, friends and health care professionals. They can also find support through the Self-Help group for patients and families. The mutual support and encouragement provided in the group help them get out of the trough of pain.

It is my hope that this book can inspire you all. Even when we cannot change this painful situation, we can at least change the mentality of facing pain. Through the learning points suggested by the COPE instructors at the end of each story, you can search for a new path towards a fruitful life.

Dr Ko Wing Man, BBS, JP  
Secretary for Food and Health

### **A cheerful heart is good medicine**

A cheerful heart is good medicine, but a crushed spirit dries up the bones. (Proverbs 17:22) The main characters of the story truly lived out the meaning of this Bible verse. Chronic pain made them lose, but also made them gain. With the help of healthcare workers and as a result of their own efforts, their closed hearts were opened again. Joy began to fill their hearts, lubricating their dry hearts due to anxiety.

Above all else, guard your heart, for everything you do flows from it. (Proverbs 4:23) Research has shown that people may experience pain in two ways: from bottom to top, i.e. when the body is stimulated, signals will be sent to the brain. Another is from top to bottom, i.e. the brain sends out signals to the body, and the body can experience pain. Our expectation, cognition and attention can affect the experience of pain. The Comprehensive Outpatient Engagement Programme (COPE) teaches patients to adjust their expectations in periods of pain, adjust their hearts and minds and their focus in life so that they can relive their own blueprint of life.

Because of COPE, a dry heart was lubricated, a forgotten heart was found again. Despite the trials and the thorns in their flesh, they can reignite their passion for life. I truly believe their stories can benefit others and be a blessing to others.

Rt. Rev. Dr. Thomas Soo Yee-Po, JP

Former Alice Ho Miu Ling Nethersole Charity Foundation Board Chairman (2012-2015)

### **The invisible pain**

Chronic pain is commonplace among urban people. Despite being common, there is a lack of understanding of this disease. Often one has to experience a similar kind of pain in order to understand what “invisible pain” means. I have experienced various kinds of pain and thus can understand its bitterness. A diabetic patient will have his/her blood glucose level tested by pricking the finger for a blood sample. A hypertension patient will have his/her blood pressure measured by using a blood pressure machine. However, pain cannot be measured objectively using machines or test papers. Pain can thus be misunderstood as something psychological in nature. Such misconception of pain can further increase the burden on patients, who at their most needy moment in life, are not able to gain the trust from family or friends. They feel rejected and devastated, which further adds to their physical pain.

Whatever the chronic pain is, patient is in the best position to help themselves, followed by family members, and lastly the healthcare workers. The role patient play is of utmost importance. Similar to chronic disease sufferers, the chronic pain patients hope to gain the recognition, support and trust of healthcare workers and family members so that they can face the pain with courage and be set free from their worries. This is part of the therapy. Some stroke patients cannot even express their neurological pain, thus the importance of the trust and recognition by family members and healthcare workers. I hope that the touching stories in this book can help answer the queries and let us have a better understanding of chronic pain, which can help these patients more effectively.

As a physician who used to work in the field of pain medicine, I am very pleased to witness the birth of the self-help support group for chronic pain patients and families. Chronic pain patients have the most important role to play in this process. Once they recognize the fact that it is impossible to eliminate all pain, what is important for them then is to learn how to cope, pick up their hobbies, and live out a quality, meaningful life. Only the patients themselves know best about the movements that will cause less pain, and also about how to live with pain. I believe that this patient self-help support group can enhance the mutual support among patients, and I believe that this book can help many pain patients to live a new life.

Let us continue to strive for the betterment of pain patients in their treatment process.

Dr Hung Chi Tim , JP  
New Territories East Cluster, Prince of Wales Hospital Chief Executive

## **Preface 4**

### **Turn Pain into Power: The Importance of Self-Care**

Everyone suffers from pain at various times throughout their lives, whether due to vaccination during childhood, fall in the playground, different kinds of injuries while growing up or labour pain with childbirth. Thus we are all familiar with the feeling of pain. Though pain is an unpleasant sensory, we recognise that it is part of life. When the pain experience is short-lived, we will have the sense of control to overcome the time limited pain and suffering. If the pain persists more than three months and develops into chronic pain with time, it has the ability to erode our psychological well-being. How should such pain be coped with?

My deepest appreciation goes to the concerted effort of the multidisciplinary pain team at Alice Ho Miu Ling Nethersole Hospital and the Nethersole Institute of Continuing Holistic Health Education in working together on this book. The book covered the physical and psychological treatment and management of pain from the perspectives of patients and health care professionals. A number of patients have shared their journeys in conquering and living with pain with our readers. Many pain patients, who are often misunderstood by others in their daily lives, are under huge pressure. They feel that others do not feel their pain and live in chronic frustration and desperation. I hope that pain patients can learn from these real life stories, understanding that they are not alone on the path to recovery. Readers can get to know about the Comprehensive Outpatient Engagement Programme (COPE), learn various ways to reduce pain, develop positive thinking and mental resilience and in the end, take good care of themselves and live with pain.

Pain can come all of a sudden, it is a matter of degree in severity and there is individual variation in coping with pain. The best support to pain patients is our empathy, understanding and concern. The Bible says, "Do to others as you would have them do to you." (Luke 6:31) "Yet I am always with you, you hold me by my right hand." (Psalm 73:23). We can give strength to body and soul of patients, accompanying them to overcome hurdles in their health journeys. Through the support of family members and friends, and the mutual encouragement in the patient self-help support group, chronic pain patients can restore their confidence and self-esteem, and live out a fruitful and blissful life.

Dr Beatrice Cheng

Former Hospital Chief Executive of Alice Ho Miu Ling Nethersole Hospital and Tai Po Hospital (2010-2015)

## Prologue

First of all, I would like to thank Alice Ho Miu Ling Nethersole Hospital Charity Foundation for their generous donation over a decade ago. It has made possible the multi-disciplinary pain management team<sup>1</sup> at the Alice Ho Miu Ling Nethersole Hospital went to Australia to learn the special treatment in order to assist patients in facing chronic pain and its complications. These help re-establish the healthy attitude and living of patients. In 2002, the team initiated the Comprehensive Outpatient Engagement (COPE) programme by putting their knowledge into practice. The scheme provides a new therapeutic direction for chronic pain patients in Hong Kong.

COPE programme is a rehabilitation programme based on the cognitive behavioural therapy that pools together different healthcare professionals and integrates multi-layers of knowledge and skill into the same theme. Course participants should understand the purpose of the course and their own responsibilities. If patients are willing to live with pain, they will be invited to the programme upon assessment. As such, all course participants have one thing in common – their motivation to change. Since some patients who lack the motivation to change the vicious cycle that affects their way of living cannot join the programme as a result, the team wants to find out the factors that can help them. Thanks to the funding earmarked in 2011 by the Nethersole Institute of Continuing Holistic health Education (NICHE), a research that explores the motivation for change was supported. The research focuses on motivation for change among chronic pain patients. Through in-depth interviews and qualitative analysis, it is found that their motivation for change comes from various sources, including: family, never give up thinking or personality, Christian faith or religion<sup>2</sup>. These findings are very helpful in understanding patients' motivation for change.

At the 10<sup>th</sup> anniversary of COPE programme in 2012, guests were all moved by the experiences shared by chronic pain patients. We thus decided to publish these stories in order to encourage other patients, and to bring hope for both carers and healthcare professionals. I thank NICHE team and Dr Luk who turned these case studies and conversations into stories. My thanks also go to patients who are willing to participate in the research and to share their experiences.

The book can be divided into two parts. The first part are contributed by the chronic pain patients including an introduction of the patient self-help support group, fourteen stories from COPE graduates which are followed by the responses and practical tips from the COPE programme instructors and the holistic care team members. This is end by the COPE programme graduates'

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<sup>1</sup> . The team comprises pain doctor, pain nurse, clinical psychologist, physiotherapist, occupational therapist, medical social worker and chaplain at the pain management center, Alice Ho Miu Ling Nethersole Hospital in the New Territories East Cluster Hospitals.

<sup>2</sup> Lam, C. S., Chen, P. P., Wong, C. M., Kwan, S. M., Ma, M., & Hui, P. L. Case studies: Turning point – a qualitative study of motivation of change in Hong Kong Chinese chronic pain patients. Poster session, International Association for the Study of Pain (IASP) 15th World Congress on Pain. Buenos Aires, Argentina, 6–11 October, 2014.

encouraging words upon completing the programme. The second part is written by four authors: Dr Lee who is a pain doctor shares the difficulties of chronic pain management, Ms Ma who is a pain nurse introduces the historical development of COPE programme, Dr Luk who is the director of NICHE interviews the instructors of COPE programme, Chaplain Hui who is the Clinical Pastoral Education trainer explores putting the spiritual care into practice. The input of the hospital chaplain who is not included in the original Australia scheme is a unique feature in the Hong Kong programme. Dr Luk then further discusses on the concept of holistic health that enhances our understanding of holistic care. This book concludes with encouraging words from department heads of the hospital.

It is hoped that this book arouses people's understanding and care for chronic pain patients. It is also our wish that patients who are suffering from chronic pain can be inspired by the experiences of these COPE graduates, treat pain as a friend, and learn to live with it to embark on a fruitful life.

Dr Lam Chi Shan

Project coordinator

NICHE

## Chapter 1

### **COPE club – Chronic Pain Patients Support Group**

Mr Simon Tam (Team representative)

#### **In the beginning**

The COPE club began in 2012 after the 10<sup>th</sup> anniversary celebration activity of the COPE programme at Alice Ho Miu Ling Nethersole Hospital. The course participants were excited at this event, and recounted the good memories at the course as they supported each other, and learnt from each other. Though we came from different classes, a simple hello, a nod or a smile would already strengthen our relationship as alumni. The event was then full of care, love and positive energy. Soon after the event, the New Territories East Cluster Pain Management Centre and Health Resource Centre started to prepare for the launch of this support group. The purpose of the club is not just to extend the self-management philosophy of the COPE programme, but also to reinforce the spirit of mutual support and encouragement. The group helped reinforce the connection between us and other patients, family members and volunteers. This facilitated self-help and our reintegration into the society.

#### **What is COPE Club**

The naming of the club reflected our outlook and the transformation we underwent since the participation in COPE programme. From our uptight expressions to smiling faces, every step we took is not an easy one. Members later named the group as a club because our lives have changed from a mono-colour to a multicolour pastel. We lived a life with pain but not suffering as if being placed in a club. We no longer focus on the pain, but live happily.

#### **Our participation**

Not only does the club comprise course graduates, but also other pain patients and their family members. The club gathers together carers and patients from different walks of life. While members understand that the group will not completely cure the pain, the mutual tolerance, respect and support shown has healed our hearts and lifted our self-esteem so that we will cherish our present moment. The lively activities of the group have benefited us physically, spiritually, socially and psychologically. In a group without hierarchy, people feel especially relaxed and even the family members can feel a lively atmosphere.

#### **Last words**

I truly hope that the experiences of our members can provide a source of inspiration and a ray of hope for readers. Alice Ho Miu Ling Nethersole Hospital New Territories East Cluster Pain Management Centre launched the COPE programme as well as this COPE club so that we can continue to live a new life with those in pain. I truly hope that these members can continue to work hard, raise their self-esteem, and create impact in others' lives. Through bringing in new members,

we can continue to promote the concept of self-management, reduce the burden of medical staff in order to create synergy effect.

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## Chapter 2 Story 1

### **‘I am sick with medication’**

Simon, a businessman, in his fifties. Married with two children, life was easy enough until a car accident in 2006, during which a sports car bumped into him. He was knocked out with serious injuries to his pelvic bone and limbs. With numerous surgeries he recovered from the injuries, yet he suffered from a severe burning pain since the accident. Four years later, he joined the COPE programme.

#### **Hopes totally shattered**

My body suffered from bone fractures in different areas due to a car accident almost five years ago. Besides the bone pain, I also had a nerve pain. As I underwent various surgeries, I always hoped that the pain would go away. But my hope was always met with disappointment and frustration. Four years later, I became so frustrated that I decided not to undergo further surgery. My experiences over the past few years were indeed very painful. I felt that I was not in control, seeing this doctor one day and the other therapist on the next. Sometimes I would simply stay home without doing anything.

I simply could not do what I want over the years. One doctor would ask to have an appointment with you, and another would ask for a medical check-up. Then the therapist told me to do this in the morning and to do that in the afternoon. It seems that all activities have been pre-arranged by others. While these activities are meant for my healing, I didn't really see its effectiveness. My life is full of suffering. It entails not only physical pain, but also a spiritual burden. I am like a wandering soul, not knowing what I am doing. I need to wait for more than two hours to see the doctor at the clinic, and then a long wait for the prescription. The doctor asked, are you in a lot of pain? If so, increase the dose. This has become an annoying routine.

#### **Indulged in medication**

During the worst of the days, I took more and more painkillers and psychiatric medicine. I even have to take sleeping pills during the day as the dizziness would cover the pain. But the pain still hasn't disappeared. I still woke up with pain every morning. I will doze off after reading a few lines, which may be caused by medication. When I woke up, half of the day already had gone by. In the end I had to take painkillers three or four times a day, and I spent my day half awake.

Such pain had stopped me from living a normal way of life. I lost my self-confidence completely, and I easily lost my temper and was dissatisfied with everything. I felt that the world is full of injustice and unfairness. Even trivial things could spark off my negative emotions. I nearly beat up a security guard, quarreled with people and ended up in police stations more than once. And my body would be in more pain when I had these emotional outbursts.

#### **Self-isolation**

I would simply isolate myself when I became depressed. Though I was idle all day, I did not want to see or even talk to my family as our conversation will inevitably surround the topic of pain. While I want to avoid talking about pain, my family would still ask “Are you in pain? Do you feel unwell?” They would then remind me to do more exercises or other things, which further add to my pain and made me feel I was in a serious condition. My daughter was at secondary four and my son was at primary six when the accident happened. For a long period my children were doing their homework as they came to visit me at the hospital. Over the years I lost the opportunity to accompany their development as I underwent no fewer than twenty surgeries at the hospital, and if I was at home I felt only half-awake and I could not care too much about what my children were up to. I hate this feeling of being helpless with others and stick to myself. In fact, I only had limited recall of what happened in the past six months, which may be due to the fact that I want to forget all this pain.

Over the years I accumulated a lot of anger. I might easily lose my temper especially when I was in pain. I said to myself, I am a patient and it is reasonable to vent my anger. While I try to control myself in front of my family members, my wife could easily tell my conditions. Even when I didn't say a word and didn't show any expression, she could tell I am not right. My family is the biggest support in my recovery period. But sometimes their concern can lower my morale further, as I feel that I am nothing and cannot do things right. I cannot stand nor kneel. Whatever I do, I often feel being monitored. For example, when I accompany my wife shopping at the market, she would reject my offer to help, “Don't try to carry things for me, otherwise you might get worse!” When I walk, she would remind me to be careful. I feel that I need to be taken care of in all the things that I do. During that time, I try to resist the identity as a patient. If not because of the pain, I should be managing a big company as an owner. I should be the one who take care of others but not being taken care of.

Besides my family, I got a lot of inspiration from friends. A friend helped me with his self-taught acupuncture treatment. He said that my case is not that bad compared to others. Recovery depends not only on medication and acupuncture, but also the right attitude. If I have a right attitude, be positive, I would gradually recover. His advice and help became a great support.

### **In the past...**

Things simply got worse while I continued to visit doctors and take pills. Then I heard from a pain division doctor about the COPE programme. I decided to join as a way to demonstrate to my wife that I had tried my best to deal with my pain, rather than having any expectations. After all, I was already desperate and would not mind trying anything. During the course, a friend of mine would chauffeur me to the hospital. I was a bit disillusioned at that point and in particular, I tried to avoid the social workers and chaplain at the programme. I often ‘forgot’ their appointment as I said to myself “I am not a patient, I can manage myself without seeing these experts.” When they offered help to me, this is just to remind myself that I am still a patient in pain.

One of the biggest benefits out of the programme was, surprisingly, the advice given by Ms. Wan the social worker. At the end of one of her sessions, she asked “Did you realize how many times you mentioned the term – in the past?” I then realized that I was comparing with something in the past, and this led to anger. So I learned to put my past identity aside and be an ordinary person. I now don’t talk about work when I met my previous colleagues. We could be friends chatting about everyday life. I am not a boss and I don’t need to identify myself as a patient or a weak person. I am who I am!

### **Renewal of my heart**

I am now very different from the past. First, I ceased all medications and no longer treat myself as a patient. I also learn to love myself. In the past I would over estimate my ability. Today I will not twist my arms into anything. I understand my limitations, physical, mental and other limitations. I come to terms with reasonable expectations on myself. I won’t do what I cannot. I will try other ways to solve problems. Thirdly, I will take the initiative to communicate with family and friends. In the past, my work is about managing others and helping others, and I did not have to receive help from others. Today I gradually accept the change in identity.

I now am able to appreciate basic things in life, I could go to restaurants and buy some stuff by motorbike and I have picked up my hobbies. I feel satisfied by just doing that.

## Response from COPE instructor

Dr M. T. Chu

“Doctor, why am I still in pain after taking medication as instructed?”

“Doctor, can you cut the medication dose? I am worried that the medicine is not good for health.”

“Doctor, I want painkillers that will not hurt the stomach, is that possible?”

The most common prescription in many clinics is painkillers. Taking painkillers has become a routine for many people including chronic pain patients who might have their pills ready at all times. But what are painkillers? What is the purpose of using painkillers?

There are many types of painkillers such as opioids, anti-inflammatories and nerve-stabilizing medications. While they might have different ways of acting, it is hard to tell which painkiller is most effective for any individual patient. Often patients are the best judges on the effectiveness. The same applies to side effects like vomiting, dizziness and nausea. Less common but more significantly, patients might experience constipation, mood swings, and even gastrointestinal bleeding, difficulties in breathing, etc. with painkillers.

So how can we tell if one should take a painkiller? Let's sort out the pros and cons with the following table:

	Advantages	Disadvantages
Using Painkillers	e.g. reduce pain, increase activity level	e.g. side effects such as dizziness
Not using painkillers	e.g. reduce side effects	e.g. cannot control pain

This is to lay open the costs and benefits of using painkillers and to help patients to decide on using medications to cope with their pain.

Beware that:

1. Painkillers cannot cure. They help patients to cope with pain but not to get rid of pain
2. Painkillers are not a fix for all. Its effect varies among different subjects.
3. Prolonged use of painkillers can lead to drug resistance, which means that its effect would wane with repeated use. This is normal and does not mean addiction to the drug.

The ultimate goal of using of painkillers is to restore a normal life. They work best when combined with other pain coping methods like positive thinking, good habits, exercises etc.

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## **Response from Holistic Care Team**

Dr Andrew Luk

Simon suffered from bone fractures in various areas and had undergone a number of surgeries and a long recovery process. His bodily pain can hardly be understood by ordinary people. After a series of surgeries and treatments, Simon had lost hope as his pain not reduced. Continual increase of dosage cannot solve the problem, but its side effects had worn him down. He felt disillusioned all day and lost any joy in life.

The imbalance in his body directly affected his mental state. Simon often felt that the world was unjust and unfair. Such negative thoughts further increased his negative emotions, making him even more downcast and full of anger and anxiety. Such change of personality was reflected in his behavior, and might further impact his self-esteem and interpersonal relationship. Such emotions could lead to physiological change, consume his energy which eventually add to his pain.

He used to live an independent life with control of his own way of living, and a person who could manage and help others. But all of a sudden he became dependent on others and a patient who could not control his way of living. The identity as a patient is something Simon could not accept. For a period of time, he avoided being in contact with family and friends, as well as health care workers.

Fortunately, his strong will and independent character, combined with the support offered by his family and friends, motivated him to seek treatment. Through the practices and inspiration offered by COPE, he rediscovered his direction in life, and recovered the meaning of life and happiness.

Today he understands and accepts his ability for mobility, and recognizes his identity and role without comparing with his past. He can also understand those in need. From his experiences, we should also take care not to overly protect the patient which can further reinforce his role as a patient. We may neglect his real needs as a patient. Family members need not overly protect him or always cater to his needs. It is very important to have good communication with patients so as to help them rebuild confidence and quicken the pace of recovery.

### **Untying the knot of pain**

Ann, aged over forty, is married with three children. She works as a bank teller. She was injured at work and had been suffering from chronic pain for two years before joining the COPE programme.

#### **Sudden change in life**

In 2005 when I tripped over in the workplace, I felt excruciating pain in the beginning. I believed that I could get well soon. The pain persisted, so I actively sought treatment. I first went to orthopedic division, then being referred to physiotherapists. The situation improved a bit, then the pain came back again. I later consulted traditional Chinese medicine, acupuncture, bone-setting without significant improvement. I could not work during the treatment process, and my employer seemed to doubt my pain. Two years later I was subject to work injury evaluation at the court, and my health has deteriorated.

A few months after my injury, my pain was still bearable, then it got more and more serious. At its worst my body became stiff throughout. I could not handle the easiest movement, such as lying down, getting up from bed and I had to rely on the help of my family members. My pain had caused great trouble in my everyday life. I have no choice but to stay home and rest. This is really an unpleasant experience. I always feel unwell here and there and did not have the mood to go out and about. When I went for physiotherapy treatment at the hospital, my conditions were unstable.

#### **Feeling stretched**

It's difficult to describe my pain, and few people understand my pain. Even more frustrating is the trivialities in dealing with work injuries. I feel extremely annoyed and anxious, thus leading to a loss of appetite and weight, not to mention insomnia and nightmares. I looked tired and worn out. I was later referred to a psychiatrist and the doctor gave me some anti-depressants. At those times I developed fear over water, which sent shivers down my spine. I remembered the floor was wet the day I tripped over. The air conditioner was broken, and the floor was extremely wet near the air outlet. I was so preoccupied that day that I did not notice the wet floor and tripped over. I did not want to go out after this injury, and lived a life of fear.

I even thought of committing suicide at one point. That day after watching the news about many lives were lost at the traffic accident, I switched off my phone and wandered to a bus stop so that no one could reach me. A bus bound for Yuen Long just arrived, and I boarded the bus and sat at the first row in the upper deck.

As the bus was moving quickly, I did not take note of any beautiful scenery. My eyes were blurred with tears. I kept weeping, thinking of being knocked down by the bus. Passengers nearby looked at me with a strange gaze. I was heartbroken and was filled with struggles. If I chose to get off the

bus and rush into the main road and get killed, the bus driver would be affected by my suicidal attempt. But I really thought about getting killed in a car accident. After all these struggles, the bus arrived at the bus terminal. As everyone got off the bus, I followed suit. I wandered around with tears. I simply had a breakdown that day.

When I went for further consultation at the psychiatric department, the doctor asked me to undergo treatment immediately. I burst into tears upon hearing that as I was petrified. I was really scared of going through treatment in a hospital. I felt like falling into an abyss. As I gradually calmed down, my husband arrived at the hospital and promised to the doctor that he and our children could take care of me. With the support of my husband, the doctor permitted me to go home with an increase in dosage. I finally calmed down.

### **Learning to untie the knot**

After being referred to the pain division, my emotions gradually calmed down after the explanation of doctors and the patient instruction of physiotherapists. I could calmly face myself and consolidate my feelings towards my family. We lived happily as a family before the accident. But the pain was haunting me and my family. My three kids who are schooling would show their worry and fear when they see my unbearable pain. What made me feel uncomfortable is that they need to look for part-time work at such a young age so that there is enough money to pay for their school fee. My children are very mature and would do some of the chores. My husband works hard during the day and takes good care of me after work. He must be under huge pressure.

I really appreciate the care and the ardent support shown by my family. I decided to continue the treatment in order to alleviate their burden.

In the beginning of the treatment process at the Pain Management Centre, I still did not know about the COPE programme until upon the referral of the doctor. This is after trying all the therapies that I know of and I thought, why not try this course. At first, I felt that the course is very special, combining theory with practice, teaching the root causes of pain and some movement practices. The drills were especially important for me because muscular exercises can relieve the tension. I benefited most when I learn about my degree of movement. Some movements such as climbing up the stairs require one to stop and take some rest before walking further. As pain is a subjective feeling and invisible to the beholder, others can hardly understand our pain and conditions. Course-mates' sharing during the course helped us understand each other and support each other.

The home assignments, given by instructors with clear objectives, became the driving force for applying these skills further. For instance, I feel reluctant just to walk on the street after the injury, though I enjoyed climbing in the past. As I am doing the course, I try to go for a hike and feel refreshed after taking in some fresh air. My sleep quality has also been improved. Most importantly, I feel much more relaxed and relieved just as what the instructor said.

I used to be bogged down by the feeling of pain and was trapped in an emotional trough. Sometimes I feel my mood swings from a valley to an abyss.

Not only did I become afraid of tripping over, I also did not dare to go out when my boss said to me during my sick leave, “Don’t often go on the streets.” I became homebound out of fear. I also feel guilty going out after hearing these words. When Mr Tse, Mr Wong and other nurses go over my concern, they made me understand not every word that people say is absolutely correct. I need to distinguish between the right and wrong, rather than being bothered by these words. They help me understand the fact that our thinking will affect our behaviour, and if we can change these thoughts, our behaviour will be back on track.

### **Untying the knot**

This programme not only enhances my ability to cope with pain, but also inspires me to rely on oneself. I need to untie certain knots myself. If I did not take the first step to try, these wires will continue to form even tighter knots. But if we try to untie them, they will be untied despite the initial challenges. When these knots are untied gradually, I have the feeling of relief, and have the hope that these knots will all be untied. After untying the knot, the rope will not be stretched anymore, and the same goes to our condition.

Though my pain is not completely gone, I did not feel so stressed as before. When I got injured, I felt I was rubbish and could not do anything. I was always under pressure. Upon completing the programme, I try to untie these knots and try to accept the fact that I could not be as good as new. I began to accept the fact that I cannot sit too long and need to stand up and move for a while to prevent the pain from escalating. I have to slow down my pace and understand that our body will affect our emotions.

I tend to lock myself up in the past. Now I will take the initiative to contact my past colleagues so that they will rejoice over my improved conditions. Though I cannot be as active as before, I learn to do things which I can manage. I accept the fact that the company cannot retain the position for me because I can no longer cope with the work.

As I understand myself better, I hope that I can still continue to know myself better as I grow old. I also wish that those patients can let go of the negative thoughts and not be trapped by mood swings. I agree with what Mr Tse the occupational therapist said: “Pain is unavoidable, but it can be relieved through treatment or medication. Can suffering be avoided? Suffering is a way of thinking, and maybe we just add to our own suffering without knowing it.”

### **Life rebuilt**

I finally understand what a relieved heart and mind is after this incident. And I learn to gradually adjust my expectations. I can now go to the outskirts and outlying islands for a hike, or travel to Yunnan province by flight. Not too long ago, I joined a volunteer scheme and tried to help others

while I am still capable. At home I am happy to see the growth of children who love and take care of me as if our roles have been changed. Caring for others and being cared for can be satisfying and joyful.

I also learn to show concern for others when they are in trouble, for example, by making a call to comfort them. I hope I can bring consolations to others so that we can support each other, and walk with them rain or shine.

NICHE

## **Response from COPE Instructor**

Dr Tony Wong, Clinical Psychologist

The consequences of chronic pain can turn into a huge knot in mind. From Ann's case we learn that not only did she suffer from chronic pain due to work injury, she also developed fear towards the work environment (wet floor). This added to her psychological and emotional burden. Chronic pain and post traumatic response are inter-connected. When she realized her pain could not be cured, could not return to her previous post, and even developed fear while on the streets, she became more and more distressed and need to seek psychiatric help in dealing with her depression and fear.

Fortunately, her family showed unending love and support during her course of treatment. They encouraged her to join the COPE programme at the Pain Management Centre which helped her walk out of the difficult times. We could see the importance of both her family's support and treatment environment in helping Ann walk out of gloomy treatment failures and restore confidence and momentum.

COPE programme is an intensive course that helps participants develop capacities to manage their chronic pain. Ann's experience in the course made her realize that the pain will not go away. She should not focus on getting rid of her pain, but rather should focus on re-establishing and pace her abilities. Her self-confidence and satisfaction significantly increased when her expectation and beliefs were adjusted. The programme also helped her reduce negative emotions so that she could walk out of the fear, low mood and helpless feelings. She became more positive in thinking and could accept that her situation is different from the past. She accepted that she could not return to her original work position. Once the knot in her mind was untied, she rediscovered orientation in her life and could take the initiative to show concern for others. She also accepted others' care for her. Her life is now renewed with new meaning and experience.

## **Response from Holistic Care Team**

Dr Andrew Luk

Chronic pain not only caused physical discomfort, but also affected a person's life. After her work injury, the situation was good and bad at times. At the worst moment, she felt stiff and could not even lie down but require the help of others in order to lie on bed. The never ending pain made her lose appetite, she felt anxious, suffered from insomnia, and developed a fear towards water. She often recalled the incident and had to consult psychiatrist. Later she even attempted to commit suicide.

The care shown by her family became the biggest driving force in her life. Ann knows that her pain and suffering could make her family suffer. In order to allay her family's anxiety and desperation, she chose to seek treatment and joined the COPE programme at pain management centre.

The clear learning objectives set by the course instructors plus an interactive way of teaching helped participants resonate with each other and support one another. This inspired Ann to help others when she has the ability. The medical team provided psychological support to her and helped her understand and accept oneself, so that her knots were untied and learn to live with pain. In the end, she learned to adjust her expectations and accept the fact that her health would not return to the point before injury. She became relieved. Though she could not work, she could still travel and be a volunteer so that she could find joy and meaning in her life.

Ann learned not only to live with pain but also learned to love and be loved. After years of suffering, her children have grown up and learned how to take care of their mother. Ann also learned to accept and enjoy the care from family. In addition, Ann learned to show concern for others who are also in pain.

We witnessed Ann's post traumatic growth. Not only could she overcome pain, but also use her experience in helping and supporting those in need. Her pain remains, but her life is full of joy and meaning.

### **SARS warrior**

Kitty, married, is a clinic nurse aged over forty. She was in good health until being infected with SARS in 2003. She felt tired easily after recovering from SARS. She had back pain and weakness in her right leg four to five months after she was recovered. She joined the COPE programme for the sake of improving her physique and reducing anxiety so that she could live a normal life again. She had been suffering from chronic pain for three years and nine months before joining the COPE programme.

#### **Total failure**

When I was infected with SARS, I totally collapsed.

As a nurse in a private clinic, some of my colleagues were infected during the SARS outbreak. I was among the first to be infected. I was not treated in Intensive Care Unit, but I need to rely on breathing machine, steroid and ribavirin. After three weeks in hospital, SARS continued to plague the community. The doctor said my conditions gradually stabilized and could return home for rest. I thought that now that my life was rescued, my body could gradually recover. However, I felt weak and pain for years after that.

Six months after being discharged from hospital, I started to feel pain over my body. My bones, back and neck were in pain. I continued to visit Queen Margaret Hospital for further consultation, medication and physiotherapy, but nothing helped. I gradually could not move and could not cope with simple chores. I felt pain from head to toes, and in the end I had to lie on bed all day. My body was very weak and my emotions gradually broke down. I cried all the time. I could not sleep even when I felt tired. I don't know what happened day or night, and I simply don't know how I spent the day. Such period lasted for two years.

I was originally a tough person. When my parents broke up, I still remembered clearly what happened the day when my father left. I said to myself, "I need to take care of my mother." So I started part-timing since the age of 12 in order to finance my studies and to alleviate the burden of my mother. I used to stay healthy. Because of my positive attitude and diligence, I always strive for excellence. Now that I suffer from pain, I became extremely frustrated and lost the momentum to work.

My mother and husband loved and cared for me a lot since I contracted the disease. My husband owned a shop in the past, and its business was so seriously affected by the SARS outbreak that he closed it to keep me company during that time. My mother would prepare soup and cook for me. I felt guilty when I saw that my husband's work was affected and my old mother had to labour for me. Their care became my psychological burden. In addition, my family members easily triggered

my temper when I was seriously sick, and emotional outbursts then followed. I started to have the thought of committing suicide after a period of suffering from sickness, mood swings and pain.

### **Suicidal thought**

Such suicidal thought did not come suddenly but have been lingering for some time.

I felt I was a loser with a weak body coupled with job loss. I lost orientation in my life and became the burden of my family. Such is a life without meaning, so why not commit suicide? I already thought about burning coal at home and was ready to take action. At that time I still had some consciousness, so I phoned up the medical social worker and told him my situation. In the end, this saved my life, and I was able to make appointment with a psychologist immediately. I was then referred to the psychiatric department at the Prince of Wales Hospital.

My emotions stabilized after visiting psychiatrists and taking medication. The psychiatrist suggested that I should continue working, and my previous employer showed a lot of support to me by offering part-time work for a few hours each week. I used to love my job at the clinic before the disease as this job gave me recognition and I treasured the harmonious relationship I had with patients. I had a clear direction at work and the income received could give me a sense of satisfaction. But this time when I resumed work, I had sleepless nights and nightmares and I felt extremely tired and fearful. As I had to stand for long hours at the clinic, my feet could not bear and my hands continued to shiver. I could still dispense medications, but I could not help patients with injection and vaccination. I could not cope with tasks that I used to be familiar with. I had to accept my conditions and be thankful for the opportunity given by the doctor at the clinic.

### **Self-reflection**

Medication could on one hand stabilize my emotions and calm me down, but on the other hand I felt that I could not think properly at all. I started to say to myself: "I don't want to be like this for the rest of my life. How can I continue to live like that? I cannot continue to live a life without thinking. What should I do? How can I help myself?"

There is a patient self-help group among SARS patients and we had gatherings occasionally. These patients had conditions worse than me. Some of them lived positively and resumed their work. Some lived an unhappy life. I asked myself, "What kind of life do I want?" I could accept the fact that my body became weaker and my physique could not return to the level before the disease. I had to face the reality, though this is not what I want. I know my limitations, while at the same time I still live a happy life despite such limitations. I do not want to blame others, but I understand I need to learn not to cast blame on others too.

I received medical and psychiatric treatment at different hospitals for three years, but my health conditions did not have much progress. I started to feel angry. I then heard of the pain management

centre from some sources and I asked the doctor to refer me there, as I did not want to give up on any chance for treatment. So I was referred to the pain management centre at Alice Ho Miu Ling Nethersole Hospital.

### **Driving force**

We human beings are contrary in nature. On one hand I asked to be referred to pain management centre, on the other hand I was not too serious about it. After suffering from pain for two to three years, some doctors simply did not believe that I suffered from such pain. They said I was in pain due to psychological reasons. How can I not feel disappointed?

Other than offering medication, they arranged me to join the COPE programme. I was reluctant at first, because they required me to do exercises and write journals. I really did not know what they were up to, as I only hoped to cure the pain. I thought of giving up. As I felt the encouragement and help from healthcare professionals, I gradually accepted the programme.

I was particularly moved by one of the doctors whose words I resonated with. He said, “Your pain is real, real pain! Pills do not necessarily help you, so you have to befriend with pain, see pain as your relative or friend. Your pain may stay with you for life. When such pain stays with you, you have to learn to live with it.” Nurse Ma encouraged us to do exercises and said, “If you are in pain, then take a rest, and shorten the standing time. Set a clear objective for yourself and set a time for standing, which can be half a minute or several minutes. You can then gradually increase the duration by one or two minutes each time. You need to persist and continue to work on it at home.”

I feel pleased when I met other groupmates every time I visited the pain management centre. We worked out together, went jogging together and would talk over issues. I had a goal at the programme which is better than idling my time at home. The pain was still there, but I became more joyful. I think joining the COPE programme is a turning point in my life, giving me the momentum to live and motivating me to continue with the path to recovery.

### **A new chapter**

When the course finished, I felt that I need to continue to work on something, so I joined another programme on self-learning. This took a few years to finish and I completed various programmes. When I shared with my friends about my pain problem, they encouraged me to do volunteering work. I began serving as a volunteer at elderly homes. I feel I am of use when I am able to help others, there is joy as well as direction in my life.

My life is filled with peace. I could take a walk for one and a half to two hours each day before taking a rest. I would also do some volunteering work on a regular basis. I still suffer from mood swings, but at least I can manage them. I now do not feel the pain most of the times, except when I made a lot of movements or when I am tired do I feel a bit of pain. I would reduce the use of painkillers as I already learn how to live with pain.

On one hand I accept the limitations in my body, and on the other hand I affirm my ability, because at least I can still help others. When I work with the volunteering team, I would share with them my limitations and need time to rest. They are understanding and show concern for me. Sometimes when I encounter people who are troubled by pain or emotional problems, I would share my own experience with them to encourage them to face the issues and undergo treatment.

NICHE

## **Response from COPE instructor**

Ms K. M. Wan, Medical Social Worker

Disease is horrible. No one wants to get sick, which is a normal way of thinking. But if we get sick unfortunately, it is only natural to have fear, anger, and feelings of withdrawal. Behind these emotions we would blame ourselves for being so unfortunate. We then summon our courage to encourage ourselves with the hope that the disease will go away and our health will be restored so that we can go back to our normal routine. We always encourage ourselves and encourage others in this way.

However, when the disease is not cured, our self-reward mechanism will be tested. Prolonged sickness, our confidence will be reduced, and our emotions may collapse eventually. Feelings of helplessness are born this way. Usually people do not want to be torn by diseases. Kitty is no exception when she thought that the only way to stop the disease from wearing her down is to kill herself.

It is rare to have such suicidal thought immediately after getting sick. On the contrary, people like Kitty want to commit suicide not out of an impulsive thought but after a series of considerations before acting on it. It takes a long path before one could finally commit suicide.

So we will remind patients incessantly that there will always be people who can offer help if they ask for it at times of emotional breakdown and confusion. There will be a way out when we face the difficulty together. My "Survival Kit" for Kitty in such times contain words of encouragement and ways to seek assistance, such as the 24-hour helpline and the contact number of medical social worker so that the patient may find them useful one day.

Fortunately, Kitty still had some consciousness at the critical moment, and remembered the advice from the medical social worker and called us in time. The interventions given by the medical social worker were as follows:

1. The medical social worker listened to her situation and showed empathy and concern for her, so that she could pour out the hidden depressing thoughts and the worker could provide her with emotional support.
2. The medical social worker guided Kitty to reveal her intention to commit suicide, her plan and determination so as to evaluate the risk. She reminded Kitty to postpone any irreversible and serious decisions. The medical social worker also helped Kitty in seeking other positive solutions so as to make her feel hopeful, that she could find a way at such difficult times. At the end Kitty declined such suicidal thoughts.
3. When Kitty rejected such suicidal thoughts, the medical social worker helped her find assistance from other sources such as clinical psychologists and psychiatrists, so that she could get help from other professionals. This multi-disciplinary approach helped Kitty get out of this emotional trough.

To be honest, healthcare worker prefer patients finding the "Survival Kit" not necessary at all. But we need to prepare for the worst and equip our patients accordingly, so that they would not embark on the road of no return commit suicide as they walk through the valley of shadow of death.

NICHE

## **Response from Holistic Care Team**

Ms Fok Sum

The SARS outbreak seriously affected Kitty's health. Her life was thrown into a dark age. Originally a hard-working, positive and responsible person suddenly came to a halt, losing all her orientation. The support from her husband and mother became her burden and made her think of committing suicide. Fortunately, her positive attitude made her strong in tough times, and a phone call saved her life. After some self-reflection, she decided to face her pain, fatigue and mental problems with a positive attitude. She even initiated to have treatment at the pain management centre and started a new chapter in her life. Kitty believed that joining the COPE programme was a turning point in her life so that she gained the momentum to live. I would say that she chose to self-help, and initiated to seek help from others, then to help others. This attitude is the real driving force behind her transformation.

We learn from Kitty's example how to face suffering. First of all, we need to help ourselves and seek ways to solve problems. Kitty decided to seek help from medical social workers at the most critical moment and eventually saved her life. In addition, we could still reflect on ourselves even when we are haunted by pain. However difficult the situation, we could choose to face problems squarely, and seek out possible solutions in reality so as to live a happy life within limitations. Take Kitty for example, she did not give up any treatment methods and initiated to seek the help from pain management centre and joined the COPE programme. Secondly, the support of family and friends are very important during tough times. Thus we should maintain our relationship with family and friends. Last but not least, we should focus our attention on people who are in need. Kitty found that helping others brings joy and meaning in life. Suffering can be a blessing to one another.

### **The power of companionship**

Yuk Lan, aged over thirty, is married with two daughters. She is now an operation officer at MTR. Since the car accident in 2004, her neck and shoulder pain was so serious that she had to resign from her work at elderly home. Prior to joining COPE programme, she had been suffering from neck and shoulder pain for three years and two months. She joined COPE for the purpose of improving her sleep quality and managing her temper.

I was knocked down by a car in March 2004. I considered myself “fortunate” when I was knocked down by the car, because I only sustained face and leg injuries. I was discharged from hospital upon X-ray examination which did not show any bone fractures. The doctor said that my condition was fine, so I felt relieved. Two weeks later, I felt a bit dizzy, and my neck and shoulder started to feel stretched. Initially, at the beginning of physiotherapy and bone-setting treatment, I was full of confidence, thinking that I should be alright and could recover quickly at a young age of thirty something. But the situation only got worse, and I felt so unwell all that time. I could not sleep and had a very bad mood. The pain can be likened to being pricked by a needle. I could not stand nor sit properly, nor could I lie down comfortably. I started to look for various treatments, including injection and physiotherapy in western medicine, as well as bone-setting, acupuncture, massage and food therapy in traditional Chinese medicine. I consulted over twenty doctors within only two to three years, and spent nearly all my savings on treatments. I said to myself, I am only thirty-something, how can I survive at forty, fifty or sixty? Will I suffer from pain for a life time?

### **Indescribable pain**

I remembered what my husband said when I kept seeing the doctor. “Why are you visiting doctor for a long time?” My mother said, “You have been visiting the doctor for six months. Why are you still suffering from pain without progress?” I felt really bad upon hearing these comments. For three months I had to rely on the disability grants provided by the government. This made me feel bad.

I used to have good relationship with my neighbours. Since the pain I dared not go out, and I did not want to have any contact with them. I was afraid of being asked, “How was your pain?” They would not understand when you told them how painful it is. Some even showed expressions of disbelief, saying, “I wonder if this is real.” Even my best friend whom I have known for nearly twenty years said, “Is your pain something psychological?” Of course not! When my friends invited me for gathering and paid for my share so that I could save up for medical consultations, I would feel uncomfortable. Over the years, I had continuous consultations without ever curing the pain. I cannot sit or eat properly. Nor do I feel comfortable talking about my pain. I would rather stay at home and avoid going out.

### **Why me**

My overall health condition got worse when I stayed at home. I had bad mood and easily lost my temper. I always asked, “Why me? Why this had happened to me? Why such misfortune would happen to me? Why bad people did not suffer from these circumstances?” I kept asking why, and I felt no one could really help me. My daughter was only six or seven years old when my pain started to affect me. Before the injury I never scolded her. After the accident, I would lose control when my pain attacked me, and I would immediately scold her. In hindsight, I had lost control. I could not take good care of her at the time when she needed the care and love of mother most.

I even fainted on the street when I was at my worst condition. My neighbour immediately lifted me up and helped me sit on the chair, and put ointment on me. I often felt tingling in head, probably due to the damage to the third or fourth cervical vertebrae that put pressure on the nerve. My mind was always heavy, and my shoulder was like burdened with a thousand kilograms. I was wobbly in my footsteps, and I always thought of lying in bed. But then I felt unwell after lying for a while. But when I got up, the pain did not go away. I really felt lost, and even had the feeling of life is like death.

### **Suicidal thought**

I thought of committing suicide too. When I was waiting for the train back home, I had the impulse of plunging into the railway. I thought, “Why on earth am I full of suffering?” I did not make the move in the end, as I thought, “If I jump, what happens to my two daughters? I have the responsibility to take care of them after giving birth to them.” My eldest daughter was then fifteen to sixteen years old, while my young daughter was less than ten years old. If I die, my husband could still take good care of himself. He could still remarry. But my two daughters would then be left with no mother. I then thought of those who committed suicide died a horrible death. I withdrew this idea immediately. An idea flashed through my mind, “People with cancer could be cured, then people suffering from pain could also be cured.” I then remembered what my supervisor said to me, “If you are really unwell, you could change the duty roster with your colleague, or take a rest at lunch break. Don’t worry, tomorrow will be another day.” After a series of inner struggles, I gave up the idea of committing suicide.

### **Self-help and mutual help**

I benefited greatly from the COPE programme. The doctors listened to my case patiently. Only when I was listened to that I believed my sickness was not a lie. I felt much relieved afterwards. As I began the course, I realized that there were a lot of pain patients like me. When we were asked about our pain, the course participants were able to describe their pain, and they were mostly chronic pain patients. If people were not in pain, it would be hard to describe such pain or understand such pain. But we resonated with each other once we had the chance to share our pain. Though this could not reduce our pain, at least we felt better through this mutual recognition and understanding. What we learned at the programme could be applied in everyday life. Once there was slight improvement, I had the determination to improve the situation.

Joining the COPE programme helped me understand each incident from various viewpoints. When bad things happen, we could try to find out the good things out of them, and would feel more relieved afterwards. This is a form of self-consolation. For example, when I saw that some patients were in conditions worse than mine, I would feel that my pain was not that bad, at least I could walk and run. Though misfortune happened to me, my daughters are still in need of me. My good neighbours are also very willing to help me. I am not a hero, but my life is still full of meaning.

My course-mates are still in contact with each other two years after graduating from the course. They would support each other and comfort each other. “How are you?” “Well, I am fine. Nothing much.” “Take care and don’t go on the streets too often.” “When there is typhoon, the affected area would be in pain and is swollen.” “If in pain, don’t run, don’t work out at the moment.” One could gain comfort and support through these conversations.

N I C H E

## **Response from COPE instructor**

Ms Emily Cheng, Medical social worker

The intervention approach in this treatment helps participants explore their own selves in a safe environment. The process is full of tears and joy, full of ups and downs. The interaction among cell group members is a key element in the success of self re-discovery. We instructors are pleased to see the growth of Yuk Lan in this process – from doubting oneself to breaking through oneself.

### **Doubting oneself**

Yuk Lan used to be a capable mother – she was a good housewife and a responsible worker. After the accident, she suddenly lost her temper and resort to physical punishment to her daughter. She also could not fulfil her work duties. She used to earn money for the family, but now, as a chronic pain patient, she spent all her savings on treatment. She started to doubt herself and others. She felt that this was an unfair arrangement by God. These doubts led her to radical thoughts, and made her feel sceptical towards her existence and even led her to think of committing suicide.

### **Knowing oneself**

She had the opportunity to share her painful experience, thoughts and feelings in the self-help group. Through the guidance of her instructors, she started to challenge her irrational, negative thoughts and beliefs that made her feel impossible. The response of participants made her feel being understood and accepted. Their interaction helped her feel safe and develop a sense of belonging. Such experiences were precious to Yuk Lan, so that she had the strength to walk tall and know herself, including her inner fear and dark side.

### **Accepting oneself**

After knowing oneself, the next step is to face one's situation. Thankfully, she was able to distinguish between what can be changed, and what needs to be accepted. She was determined to change certain things, including her temper and behaviour, her suicidal thoughts and negative thinking. She honestly accepted the fact that she may have to sustain such pain for life, to live with pain for life. After accepting such unchangeable fact, she felt relieved and refreshed. Now she can accept her real self, not to compare herself with others and not to blame others. In the process, course-mates kept her company by encouraging her and supporting her, so that she no longer felt lonely or sceptical, but became courageous to face every day.

### **Develop oneself and break through oneself**

Lastly, Yuk Lan had to accept the fact that the past self (before the accident) could not be restored, while the present self is bound with limitations, limitations brought about by the chronic pain. But she could challenge herself and strive to take control of her spiritual and mental freedom, and face her life in a positive way. She found that the future self is in her hands, and so she tries to

breakthrough this self. She changes from being an apprentice to a graduate, and she could testify her transformation in front of the new course-mates, and shared her experience of being in pain but not in suffering.

NICHE

## **Response from Holistic Care Team**

Dr Andrew Luk

Yuk Lan's painful experience could reflect the unstable and continuous nature of this sickness which could hardly be understood by others. The sickness not only brings her physical pain, but also psychological burden such as anxiety and anger. Patients gradually lose the function in a society, and would easily feel shame and guilty, and even feel lost in the face of such suffering. Yuk Lan thought of committing suicide, but her sense of responsibility towards her daughters, and the care from her friends became the driving force for her continuous survival. The support of healthcare workers also gave her encouragement and recognition, especially in rebuilding her positive thinking. Peer support also plays an important role here in her treatment process.

The sickness would bring about pain, negative thinking, mood swings, change of social role and meaning of life. This is not an easy journey for chronic patients. In the treatment process, peer support and encouragement often becomes a big source of motivation. Research has shown that the support and encouragement by peers could help patients realize that they are not alone in this the process of recovery. The self-help group offers opportunities for social interaction. Through sharing of experiences, patients can learn from each other and support one another. I have conducted research with an interactive support group of chronic patients, and found that participants benefited greatly in physical, psychological, social and spiritual aspects. The findings also showed that such support group can have a therapeutic role and provide long term positive impact to patients.

### **Our family – positive energy, negative energy?**

Maggie, aged over forty, is divorced. She works as a taxi driver. After a car accident in 2008, she felt back pain, which was then extended to hip pain. There were good times but also bad times in her situation. She joined the COPE programme and hoped to have in-depth knowledge of the chronic pain and to learn some techniques. Prior to joining, she had been suffering from chronic pain for over a year.

A car bumped into my car in 2008. I was still conscious at the time, but felt pain in hands and legs. Sustained coccygeal vertebral fractures was later confirmed. I was sent home after being hospitalized for six days. My pain gradually became more and more serious after returning home. For example, I felt pain and numbness in legs while sitting. The whole of my back was in pain. At its worst, I felt back pain while yawning and coughing.

#### **Feeling depressed**

The orthopedist gave me painkillers and referred me to physiotherapist, but they are not much effective. I tried acupuncture for three months and could see some results. Hydro-therapy offered by the physiotherapy department did help a bit, especially when patients shared their experiences with each other at the treatment, as this would make me feel better. I tried occupational therapy in 2009. At first I was very positive about it, later I felt depressed when most people had completed their treatment, and even worse when my therapist suggested me change to another job.

My two daughters were still at school when the accident happened. I was under huge pressure and had bad mood, but in order not to affect them, I chose not to share my feelings with them. But when I was in a bad mood, the pain got worse. My facial expressions betrayed my feelings, and I could feel that they were afraid of getting along with me. They might think that they do not know how to comfort me or help me, and hence they hid from my presence. At the end of 2009, they often came home late, and did not come home for dinner most of the time. I felt that they did not want to see me. When my two most beloved daughters were rejecting me, I really felt I was a loser. There was a period where I could not sleep at night, and I felt so helpless that I thought of committing suicide. When I thought of two daughters, I would control myself, “No, don’t think about that anymore!” I could not allow myself to be down anymore, and I was referred to the pain management centre at that time.

#### **Turning point**

The doctors here were so different from those I met in the past. They would ask about my conditions in detail, and allow me to ask questions. They would listen to my feelings patiently, and show encouragement. This gave me a confidence boost in continuing with treatment. There were a few times the doctor would see me together with the nurse. I felt that they did pay a lot of attention

to my case. When they analysed my situation, they not only cared for my physical pain, but also my psychological situation. This greatly increased my drive for seeking recovery. They gave me some advice which did yield results after trial. I could see a ray of hope at last.

The pain management centre has a bulletin board which posted photos of those who joined the COPE programme. When I read their success stories in overcoming pain, I hoped that I could be like them one day. When my doctor introduced me to this programme, I immediately asked to join.

The programme comprised various sections which lasted six weeks, from 9 am to 4-5pm each day. At the end of the day, course participants would have one on one consultation with a doctor or a healthcare worker. The nurse would follow up on the case. The healthcare professionals looked into my case and had a lengthy conversation with me. I need to write down our discussion points after the meeting. I find it a tough job to write the process. I did not know how to put them in words, and sometimes when I had to write something personal, my mind will be filled with a lot of issues from which I want to run away. I need to force myself to write them down, as the nurse would follow up with me in our next appointment. I found that what wrote reflected some deeply hidden thoughts. I had to write them down, and to explain it myself. This exercise is a tough one, but I found that I could untie the knots one by one with this method. I was amazed to find that a lot of these knots were made by myself. Through this strategy, my knots were untied.

### **Encouraging trial**

At the beginning of the course, I had to use a stick to assist my walking. A nurse said, “If you think you must rely on the stick in order to walk, then you will always use the stick. This may lead to muscular dystrophy, and you have to suffer from chronic pain.” She suggested that I should not use a stick as an aid; instead practised walking in a slow pace. I tried and I found that it worked! She said, “If you visit Accident and Emergency (A&E) Department doctor and asked for injection immediately upon feeling pain, you will feel pain again several hours after the injection. You can actually first adjust your emotions, let your calmness alleviate the pain rather than going to A&E Department immediately.” I felt that such suggestions are reasonable and so I tried to adjust my emotions to reduce pain.

### **Mutual support and encouragement**

The mutual support among coursemates benefited me greatly. As we are all pain patients, we could easily resonate with each other during our sharing, which can be therapeutic in alleviating our pain. I found that some coursemates have situations worse than mine, while some have situations better than mine. The amount of talking time in a day during the course is nearly equivalent to a whole week of my talking time at home. At the course we felt a sense of recognition, and could easily resonate with each other. But at home, others would feel annoyed by your talk, and I lost interest in talking anymore.

## **Response from COPE instructor**

Ms Marlene Ma

### **From this case**

“The concern of family made me even feel more depressed. I felt I am nothing, and need to be taken care of. I felt I am a burden to my whole family.”

“The pressure from pain and my life made me feel annoyed. I would avoid my family members and became silent, isolated and helpless so as not to worsen my relationship with family members when I broke down emotionally.”

“I tried hard to pretend that nothing had changed and continued business as usual in order not to affect my family. But the increased pain and the misunderstanding of family members, plus a great sense of helplessness made me feel frustrated, angry and guilty. In the end I lost control of my emotions...”

Such are the feelings of pain patients. Pain is the source of pressure when patients live with family members. Pain can be a cause for disharmony with family members, and a source of frustration. Such feeling of frustration can suppress the patients’ emotions and lower their ability to cope with adversity, thus affecting their recovery. As such, improving on their relationship is a way to empower the patients so that they have the ability to face difficulties.

### **Becoming vulnerable**

Persistent pain may bring pressure to both patients and family members. Patients not only suffer from the pain but also various issues relating to the pain. These include lower pace, loss of vitality, loss of work, damaged interpersonal relationships, sleep disorder, loss of hobbies, lower quality of living, low self-esteem and lack of confidence, misunderstanding etc. These issues put pressure on the patients, and such pressure in turn increases their pain, leading to a vicious cycle. The higher the pressure, the more the pain is. With increased pain comes increased tension. Like Maggie, a lot of these chronic pain patients feel disorientated in their life and may easily lose temper and have emotional breakdown, mood swings, and even loss of control. Such a change will easily affect their relationship with family members. When the support system from the family is shaken, they become very vulnerable.

### **You change, I change**

Taking Maggie as an example, family members (i.e. two daughters) may resemble patients in terms of behavioural and emotional change when the pain strikes. So the pain affects not only one person but a whole family.

Maggie chose to keep these to herself, and she only guessed their feelings in her communication with them. Coupled with her pain and the pressure from divorce, Maggie developed negative

thinking and even believed that her daughters rejected her. When she felt a loss of energy, she simply had the thought of committing suicide. When she was pondering on this, she remembered her daughters who became the source of her life. This is the positive energy that helped her withdraw from the idea of committing suicide.

Cycle of how the pain of patients affect family's acts and emotions

1. Patients first have the pain

Patients: Fearful that the pain may cause disability, their daily focus is on the bodily pain

Family: worry and concern

2. Patients: feel a hope for recovery

Family: concern for patients, share the chores, willing to take up extra responsibility

3. When treatment yields no results, patients and family: feel angry and annoyed

4. One's daily routine is disrupted, feels out of control in life

5. Patients: feeling frustrated, angry, wants to run away

Family: attempt to rebuild a normal way of life, become indifferent to the patient

6 Patients: upon self-reflection comes a sense of guilt

Family: fear of being described as selfish and lacks understanding

7. Patients: become isolated and withdrawn

Family: become silent due to fear, leading to increased hatred or frustration

8. When pain worsens, the cycle begins again

The nonchalant response of the two daughters towards Maggie may be because they do not know how to help their mother, but not because they do not understand Maggie's feelings. When Maggie did not spell out her requests, and did not discuss issues with them, family members would feel unable to help too. Maggie did not know what help her daughters could offer, but at least she could tell them her needs and they could discuss and make decisions together. Research has shown that when family members deal with the issues together, their relationship improves, as if allies act together against their enemy.

**Wall building: pain behaviours**

Pain is a subjective experience and outsiders can hardly understand the suffering behind. When people are in pain, they will communicate to others through “the signs of pain”, including lying in bed, downcast faces, limping, rubbing affected areas, whining, nagging etc. These pain behaviours are a natural reaction upon suffering from pain, but for most pain patients these acts will gradually become habits which replace their usual way of expression or communication. Communication of their thoughts and feelings with their closed ones may be reduced, leading to wild guessing and misinterpretations, which in turn sabotage their relationship.

### **Ice-breaking: direct communication**

Pain patients can take the initiative to explain their conditions, behaviours and thoughts to family members, including feeling pressed, bound or numb, and can also explain to them how their pain affects their emotions, leading to feeling of frustration, anxiety, helplessness etc. Pain patients can make known their needs and indicate clearly how to help them deal with ongoing pain so that people need not guess their needs. This reduces miscommunication and enhances cooperation. For example, patients can say, “I need thirty minutes of quiet time.” Or they can say, “I am in great pain but I can still cope. I just need more rest.”

### **Step by step**

It is never easy to live with pain, and patients should try to discuss with family members so that they understand how to deal with this sickness. Discussion could include:

1. When patients live with pain, what difficulties do they face? What are the most difficult issues?
2. How can family members help patients so that they can deal with pain more easily?
3. What are the things that family members do that may make patients feel difficult in treating their pain?
4. What kind of assistance does family members find difficult to offer?

When family members understand and appreciate the efforts of patients, and work out some practical solutions to deal with issues, patients would be empowered with positive energy and will be more confident to deal with issues in their everyday life, which further enhances their independence.

### **The response from a carer**

To take care of chronic pain patients....

1. When you are taking care of chronic pain patients, what kind of emotions do you have?
2. How would you alleviate your emotions?
3. Have your emotions affected patients?

NICHE

## Chapter 2 Story 6

### **Bone fractures – man should be strong**

Kwok Chung, an engineering supervisor aged over fifty, has four children. He was knocked down by a lorry in 1999 when he was in duty, leading to fractures to his fifth lumbar vertebrae and right acetabulum. He felt weakness in his right leg as well as lumbar pain. He joined the COPE programme after suffering from three years of pain. The purpose of joining is to strengthen his lower limbs and improve his walking so that he can take care of his sons.

On October 7<sup>th</sup> 1999, I reported duty as usual. But when a lorry knocked me down while I was at work, my life was turned upside down.

What I most concerned after the accident is the time of recovery. I told myself I need to be cured when I can still afford these medical expenses so as not to burden my family. I underwent various treatments with this determination. As the days went by, more and more money was spent, only to find that my health has not improved, and the pain was still haunting me. My faith started to waver, and I started to feel anxious. Since my wound was not fully healed, I could not work. Without income, the medical expenses become a heavy burden. Worse still, I had not paid off the mortgage. I felt I was in a dead end, and I asked heaven, “Why the pain did not go away? When will I be healed?” I did not get any answer. It seems to me the pain had no end. All my efforts went down in drains. Will I continue a life like this in the future? I felt I am useless, a burden to the society. There is no meaning in life, why don't I just take my life?

### **On the brink of hopelessness**

In order not to make my family anxious and not to increase their pressure, I kept all things to myself. My burden could not be lifted. I bought a flat in order to improve the living conditions of my family. Now that I lost my job and ability to earn money, and my wife's income could only pay off the basic necessities of our family, I could not even pay off the mortgage. If this situation continues, should I rely on government's assistance? The bank chased me for payment from time to time and put much pressure on me.

One day, the call from the bank came through again when I was waiting for a bus. I dared not answer it, but my whole body simply tensed up. I murmured: what should I do? No job, no income ... how can I pay off my debts? The only way out is death. I was having a mental block. I paced up and down in the station. People who witnessed my abnormal behavior showed expressions of fear. I heard a person telling the lady next to me to retreat from me. I then realized that they were avoiding me and thought I was a lunatic. My feet stopped pacing, and after a while, I felt I calmed down again. I said to myself: I am not a lunatic. I need to face what needs to be faced. I should try other solutions, and ask help from friends.

### **A ray of hope**

My good friend came to my rescue and sent me a cheque after knowing my situation. Later I asked to postpone the date of mortgage payment, and so I could breathe a sigh of relief. After much consideration, I decided to drop the idea of buying a private flat. But I truly appreciate the trust

and help from my friend. I believe my treatment at the pain management center is a gift from God. At the center, I learned how to live with pain, I also felt the care of healthcare workers. These doctors, nurses and psychologists listened to my case patiently, which made me feel warmth in my heart. This is a stark contrast to the indifferent statements made by previous doctors.

The chronic pain already made me lost the motivation and interests to do anything. When the nurse stretched my muscles, I did not have much expectations. I have tried everything already, why not try this programme. After the initial trial, I felt much relieved. After the injury, sometimes I could not sleep for the whole day. I could only lie on bed without going anywhere. My health got worse because of such, and my immunity weakened. I caught cold or flu easily, visiting doctor three or four times a week. The nurse reminded me not to continue with this way of living but to strengthen my body. So she encouraged me to go out for a walk often. I felt moved when people offered help, and I need to work hard too. I would remember the knowledge I gained at the pain management centre. Gradually I found that I am no longer so anxious and depressed. I still need medication but I do not want to rely on it. So I hope to reduce the dosage as much as I can.

### **Live with pain**

When I shut myself up at home, it was no different from falling into an abyss. After falling sick for so many years, I lost confidence in everything. To go out only after the pain disappears is not possible, so I go out with the pain. Since I cannot work, I look for volunteering work. I taught the elderly and young children English at rehabilitation centre and health centre, and I taught conversational English for injured workers at a training centre. Each target audience has varying demands. To design teaching materials according to their needs has kept me busy. I felt great satisfaction when I saw their progress. I would encourage them to persevere, which serves as a reminder for myself: do not give up, do not bind yourself up. It is more blessed to give than to receive. The experience of being a volunteer gave me a lot of encouragement, and helped me reflect on my life.

I became more confident after becoming a volunteer, and more courageous. One day, I read an advert about hiring a driving instructor. I wanted to try, but I also thought that people would not hire a limping man. I finally decided to register for the job search after careful consideration. I had to take some lessons before the written test, and some young people simply smirked, saying, "Are you really serious? May be you are here just to kill time." I persisted and passed the written test. Though I felt pain walking or climbing the stairs, I withstood the pain and insisted on not using a stick. Though I am not sure whether I will be hired or not, I believe I can begin a new journey and look for other directions in my life.

### **My choice**

I was not well off when I was young, and was lacking in clothing, food, accommodation etc., not to mention the opportunity to study. My father raised me up on his own, and I simply followed him and obeyed him without any choice. I endured all the hard times and waited for the turning

point in my life. After the injury, I could choose to live in a depressing mode. I could also try to be positive. In the end, I tell myself: it's enough to be depressed for so many years. I cannot wait anymore and it is time to stand up!

The mutual support of friends, the concern of healthcare workers at the pain management centre are the two main driving forces behind my recovery. My wife has been accompanying me since day one, and they did not have any complaints or deliberately talk about my sickness. Their overwhelming concern and consolation in turn brought me pressure and burden. What I need is their care and company according to their role. I cannot return to my previous profession, but at least I can ask for a change, for which I should be thankful.

### **Response from Kwok Chung**

I am really thankful for the pain management centre that gave me a second life. The healthcare workers showed love and professional guidance to me at the most difficult time in my life. Without them I would not be able to survive. I can hardly describe my pain during that period. I really do not know what to say but it is no mean feat to be able to lift myself up again.

## **Response from Holistic Care Team**

Ms Stephanie Wong

A person may easily lose morale and vitality, and even become hopeless after suffering from chronic pain. Not only will one's physical health get worse, one's mental health will also be affected, leading to a vicious cycle. Many a time medication could not help, so it is most important to adjust our attitude.

In the beginning, Kwok Chung was still positive about treatment. But pain was like a shadow following him from time to time. He experienced a lot of struggles before he finally hoped to be set free from this bondage and learn to dance with pain, to carry the pain while out and about. Our physical health will affect our mental health, and our mental health will affect our body. Kwok Chung was determined to walk out of this shadow and tried some exercises to alleviate his pain. He became less anxious and depressed.

While the road ahead seemed bleak, there is a way and a choice. After the injury, Kwok Chung lost his earning power, and considered himself to be useless and a burden for the family. He felt that there is no meaning in life. This is like a formula in our life. Our meaning of life depends on our ability, and our ability is demonstrated by how much we earn. Kwok Chung has set another formula for himself so that he could get rid of the negative thoughts and turned positive. He learned to receive help from friends, wife and healthcare workers. He felt satisfaction while doing voluntary work, and found meaning in his life. He learned to appreciate himself when he used a new perspective in viewing things. He carried a grateful heart when he continued to explore a new direction in life.

## Response from Holistic Care Team

Dr Andrew Luk

As the adage goes, “Life is full of challenges.” Kwok Chung encountered an accident and experienced a big crisis in life. This accident made him lose his earning power and meaning of life. But we learned a lot from his recovery process.

1. Divine help

We would generally blame others when we face difficulty. But Kwok Chung worked so hard in finding the right treatment, and he believed that this is the chance given by God. He could see the good out of the bad things. We should learn to comfort ourselves with positive thinking in tough times.

2. Self help

While Kwok Chung suffers from pain for a number of years, he never gave up. He accepted help and at the same time continued his learning process to overcome pain and change to another job in order to look for a new direction in life. This way of familiarizing with a new life is a role model for recovery.

3. Others' help

Kwok Chung being the head of his family has the role of taking care of his family members. Now he turned to be the one who received help. This is not an easy thing for a man to accept. But Kwok Chung was willing to receive help from his wife and good friends, and learned to accept one's limitations. We are not strong all the time, and have our weak moments when we need help.

4. Helping others

Voluntary work is a joyful antidote for ordinary people and patients. When one engages with voluntary work, they would turn their attention from oneself to others. Not only could they help others but they could be encouraged with increased self-confidence. This confirms what the Bible says, “It is more blessed to give than to receive.” (Acts 20:35)

I hereby wish Kwok Chung every success in his new job and in re-discovering meaning of life.

### **Sense and Sensibility**

Florence, married, is aged over forty. She used to be a kindergarten teacher.

Since 2001, she had been suffering from rheumatoid arthritis<sup>1</sup>. Her knee joints began to degenerate, and she often felt weak in her lower limbs and had been suffering from pain for nearly ten years prior to joining the COPE programme. She joined the programme in a hope to strengthen up to face her pain and to learn some exercises.

I started to feel pain in my toes more than ten years ago, and the pain then gradually extended to all my joints, including fingers, elbows etc. Each day I had a fever, and I was later diagnosed with rheumatoid arthritis. I cannot work when the pain struck me. I cannot take care of myself either. What is most unbearable is that the pain affected my sleep. I would wake up in the middle of the night when pain struck, which could be as painful as the pain from bone fracture. At its worst, my hand and leg joints, as well as my jaw could not move. I cannot even speak or chew.

Medication can only help relieve the pain a bit, and it takes two to three hours before the effect takes place. However, the painkilling effect lasts only one to two hours, and the effect wanes afterwards. This is then followed by a second dosage. I then use Immunosuppressive drug in order to alleviate the pain. I can at least walk with a walking stick without relying on others to help me. I tried many different therapies, including Chinese medicine, acupuncture, massage etc, but these cannot control my pain.

#### **Turning point**

I was extremely frustrated when I had no choice but to live in pain all day. I felt myself useless all the time. For a period I took twenty western herbal pills in a single dosage, which was really bitter and hard to swallow. I even vomited and felt nauseous after taking them. My teeth dyed blue and I could only remove the stain after brushing my teeth a few times. When I looked at the bowl of medicine, I really wanted to take my life. I cried each time after taking the medicine. There was once when I cried hysterically after taking the medicine, feeling very annoyed. I threw the medicine into toilet bowl, and I smashed the bowl to the floor. I even wanted to cut my wrist and commit suicide. I thought to myself, how long did it take to die of blood loss? How can it be quicker? If I switch on the tap and let the water wash down my wound, will this quicken the loss of blood? But this method seems troublesome. I then thought, why not drown myself in the bath tub, this may be easier.

I really filled the bath tub with water, and as I sat beside the tub, I was filled with negative thoughts.

“If I die, what about my husband?”

“Well, he can marry again!”

“What about my mother? She can still go to elderly home and be taken care of.”

I then thought, if I really died, my mother would be overwhelmed with sorrow. She, an elderly would have to witness the death of her daughter, and I am her only daughter. Spending the rest of her life in elderly home would be depressing. My mind suddenly clicked as I thought of this, and said to myself, “Am I crazy? Thinking of suicide by filling up the bath tub?” I was shocked by my behaviour and I switched off the tap immediately. I called up my friend who was very worried about my suicidal attempt, so she came to visit me immediately and introduced a clinical psychologist to me. After the consultation, I adjusted my attitude and did not think of committing suicide ever.

### **Light at the end of the tunnel**

Such never-ending pain has been a blow to myself. I often thought that I am useless and a burden to others. My husband has to take care of me on top of his busy work. He could actually marry another woman without taking up this burden. But he never had this thought, yet I am the one who had this thought. In addition, I cannot complete a lot of tasks. I lost control in everything, and I need help during meals, drinking water, toileting etc. The bodily pain plus bad mood made me lose the interests to contact friends. I am worried that I do not know how to respond to friends' consolation. I might just cry and people would not want to meet me again.

The process of pain has not been stable. For some time I felt myself slow in thinking, and even lost the ability to communicate, leading to a mental block. I can hardly understand what others are saying and cannot reply others. When I was at my most depressing time, I did not want to do anything. When I became better, I said to myself, “I am still young. I won't take my life, but I have to think of ways not to make my conditions continue to worsen. I must have self-confidence.” Then when conditions worsen, I would say to myself, “I don't care, oh no.” When I thought that my mother needs me, that I need to take care of her, my love for her became the driving force behind facing the pain. Also, my attendance at the self-help group at the rehab centre also stimulated my positive thinking. It helped me untie some knots. I am a Buddhist, and reading Buddhist books or sacred texts helped me do away with negative emotions. I sometimes felt that the heaven allowed this pain in order to help me gain some benefits in return.

My faith has helped me get out of my emotional trough, while at the same time helped me turn to positive thinking. For instance, my pain caused my job loss, but on the other hand I gained more time taking care of my mother. When pain struck, it is painful, but after the pain, I feel peaceful and joyful again. My mother used to throw tantrums before diagnosed with dementia. The sickness is a blessing for her. I believe that Buddha will protect us, and arrange the best for us even when I am at my worst.

In addition, I thank my husband for not giving me up. He helped with house chores and accompanied me to the self-help group. He learned how to help me go through the most painful period. The support and understanding of family members are most important for patients.

Since attending the programme, I became more positive in thinking, and I gained in self-confidence too. In the past, I used to think: “will I survive after walking halfway? “There was a time when I was crossing the road with my friends, my legs suddenly hardened and could not walk. I need my friend’s help in bringing me back to the pedestrian road. Since then I was scared of crossing the road, as I did not want to burden others. After attending the programme, I learned how to live with pain, and learned to use relaxation techniques to destress. I became more relaxed, and I would say to myself: whatever happens, do not worry, relax and do some stretching. I will also contact some friends to get together and join some interest classes to fill up my diary. I became more joyful afterwards.

N I C H

## **Response from COPE instructor**

Dr Tony Wong, clinical psychologist

Florence has been suffering from rheumatoid arthritis with resultant chronic pain and negative emotions. More than ten years of chronic illness made Florence lose her job and she was unable to take good care of herself. In the treatment process, she tried to control pain and reduce symptoms, but her conditions were fluctuating without reaching a cure. Emotionally she entered a bargaining stage, but she finally felt useless and a failure. She gradually was on the brink of depression and had attempted suicide. Fortunately she remembered her mother, put off the decision, and sought help from psychologist.

Florence later received psychotherapy but was still in a depressing state as the pain never left her. The driving forces behind her recovery included the following: a role in taking care of her mother, self-help group, religious faith, and joining the COPE programme.

The interdisciplinary team in the COPE programme is based on cognitive behavioural approach. Through various disciplines, coupled with classroom discussion and exercises, participants gradually achieved their goals in physical functioning and everyday living. At the same time, participants strive to overcome the negative thoughts developed as a result of chronic pain, learn how to improve their way of living and work, and solve the various problems brought about by pain. Finally, they apply what they have learned to everyday living and share their experience with other participants.

From my observation, when participants' thoughts and behaviour change, emotional improvement will ensue. Their self-confidence or self-efficacy may also increase. After the programme, their level of pain will not be fully reduced, but the distress and life interference brought about by pain could be improved. After joining the programme, Florence rebuilt her ability in daily activities. Her self-confidence also increased, helping her to live with pain.

Florence's case reflected the path that many chronic illness patients had gone through. They went from bargaining to depression, and to acceptance. Just as Florence described, it is a process where people see light at the end of the tunnel. Of course, it is also very important to know that this winding path is not gone through by the patient alone, but by a group of companions.

## **Response from Holistic Care Team**

Dr Andrew Luk

Florence, a chronic patient, has been suffering from pain, which led to depression and suicidal attempt. Fortunately, her rational thinking overcame her emotions at the critical moment, and she learned to seek help after thinking of her mother's needs. Her friends also played an important role in supporting her so that she could walk out of this difficult situation.

Taking care of her family became the biggest driving force behind her recovery. The self-help group helps cultivate positive thinking which stabilizes her emotions. In addition, her faith steered her back on track, and gave her hope to continue the way forward. The COPE programme boosted her self-confidence through a series of training, and helped her continue with the rest of her life journey.

NICHE

### **Free like a bird**

Yuk-fong, aged over fifty, is married with two sons. She was a wedding gown manufacturing designer and yoga instructor before retirement. In 2008, she started bone-setting treatment after overstretching herself in a horse-riding activity, leading to pain in neck and shoulders and headache. The bone-setting treatment actually worsened the conditions. She had to discontinue her voluntary service as a yoga instructor because of the persistent pain. She joined the COPE programme aiming at lessening her dependency on her husband and reducing his worries. She had been suffering from the pain for three years prior to joining COPE.

#### **Origin of the pain**

There was a time when my body was tossed by the air currents on plane, and such movements further traumatized my stretched neck and shoulder muscles.

Such muscle strain has been affecting me for decades. When I worked at a garment factory years ago, I had to carry tens of kilograms of stock from here to there. I also had to take care of my children after work, and thus had to carry them on my back or with my arms. When my sewing became skillful, I shifted to wedding gown design and production. The work gave on my neck and shoulders more pressure. When my two sons grew up, our family finance gradually stabilized, I decided to retire earlier to alleviate muscle tensions in my neck and shoulders. But my condition had not improved since retirement though my daily living was not too much affected by that. I still could manage to teach yoga at a community centre when time allowed. It was a way to help others while relaxing myself. My condition worsened after a horse-riding activity in 2008, and it went worst after bone-setting treatment. The flight turbulence was a trigger point that started my three-year long pain.

The overstretched neck and shoulder muscles made me feel dizzy. I felt that I had to grab others in order to walk every step of the way. When the neck and shoulder muscles on both side were stretched, my whole skull would tense up. I feel suffocated and my neck was like being grabbed tightly by someone. When I was sent to the Accident & Emergency (A&E) Department at Prince of Wales Hospital, there was no lack of oxygen upon checking. So the doctor just prescribed me with painkillers after examination. After several A&E visits I became resistant to painkillers and injections. I was then referred to general medical department and given antispasmodics, but without much effect. My neck and shoulder continued to be strained and in pain, I often suffered from insomnia and my mind went blank. My physique and spiritual health were deteriorating, and I gradually lost the ability to take care of myself. Later, I was referred to psychiatrist and diagnosed of depression. However, there was not much improvement after taking medication, rather, the uncontrollable muscle tension continued to weigh on me.

Seeing that no medication really helped me, my husband took me to see a neuro-surgeon at a private hospital. The surgeon said, "My expertise lies in neuro-surgery, but your problem cannot be solved by surgery. "With disappointment we left the hospital, I suddenly collapsed and fainted for two hours. I was then referred by the neuro-surgeon to a psychiatrist who asked me to stop all previous medications. He gave me a new prescription. My conditions had improved a bit, but my neck and shoulder were still badly strained.

I could not see much improvement after a prolonged treatment. The pain continued lingering and afflicting me. I felt hopeless in the path to recovery, and I thought about committing suicide in order to relieve the psychological and financial burden of my family.

Years ago, my elder sister and brother-in-law committed suicide in two consecutive months by jumping from height. My elder sister suffered from mental problems while my brother-in-law suffered from disability after stroke. He felt that he was a burden to the family and committed suicide one day in my elder sister's absence. My elder sister found this too hard to bear, and she followed suit. Their deaths had brought enormous pain to their children who were still traumatized by the incident. The recall of family's painful experience and the consequences thereof quickly made me put aside the suicidal thoughts. Also, my son once told me that the deaths of his uncle and aunt had caused great pain to his cousin. He asked me never to think about suicide, never to follow in their footsteps. Thus I put aside such thoughts.

### **My family is the source of my strength**

My headache and my endless pain in my neck and shoulders left me weak and helpless. My husband showed full support during this period, he even quit his job in order to take care of me, and sent me to hospital for check-ups and accompanied me to doctor's appointments. Though my husband can afford my medical expenses, I felt he must be under great pressure as I found that his hands were cold when I grabbed him when I was in the hospital. My sons did not talk much, but I knew they cared a lot for me, they just felt helpless in this situation. At my son's wedding last year, he shared that he wanted to follow his father's footsteps in marriage life taking care of his wife with all his heart and mind. He witnessed how his father never left me in sickness or in health. I was very moved by his speech.

One day, my husband suddenly said, "I actually cannot help you much. I can only support you, but you still need to walk this path on your own." This was such a hard blow to me. What he told me is the truth. I should stay strong because of their love, I should seek a way out and get out of this situation so as not to destroy the family we built together. My husband encouraged me with these words, "You survived all the major illnesses you had in the past." Indeed, I had gone through a few major illnesses and recovered completely, he believed that I could still overcome this sickness, despite a prolonged one.

### **The bird that never dies**

There was a time the pain struck me so hard that my husband sent me to the A&E. The pain was so unbearable when my muscles in the neck, shoulders and head tensed up. I was lying on the stretcher and could not move a bit. I said to myself, I am done! After several hours, my muscles started to loosen and the pain gradually stopped. I came to my senses – I did not die! I could still breathe, and my oxygen level was sufficient. I still suffer from pain all the time, and had been to A&E numerous times, but I still survived. In other words, my pain could not kill me! "Why do I still get so nervous? Injections and painkillers did not help much, then why bother to come to A&E?" The hurt caused by the pain was not endless, so I should relax. Whenever there was no pain or less pain, I should take some time out and enjoy my days.

I realized that I am an ever-living bird. When I fell, I could rise again. My strong character helped me through various difficult moments. Our life would not be without any troubles. Occasional troubles could become a good testing ground for us to sharpen our wisdom and test our patience. When I worked as a wedding gown designer, I chose to work on challenging designs because I was not fearful of challenges, which I consider as opportunities for breakthroughs. I became stronger and stronger each time. I felt that facing this pain is of no difference from facing challenges in the past. I must have the courage and determination to overcome difficulties rather than let myself fall into the abyss. I must look forward and not to regret what should or should not be done in the past.

We all are good at making hypothetical statements starting with "if". If I did not choose the career as a garment worker, or if I did not work so hard for the purpose of increasing household income, the pain in my neck and shoulders will not happen. However, these thoughts cannot help with the current situation, and would not reduce my pain in any way. Rather, these thoughts would make my husband and family members feel bad about themselves. I often reminded myself not to regret or complain, and my sister's family tragedy reminded me to always have hope in our life. We should live life to the fullest and not to belittle ourselves or deny ourselves. We should give ourselves the opportunity to make a step forward.

### **Learn to change, Get involved in exercises**

Fortunately, I was referred to the pain management centre at Alice Ho Miu Ling Nethersole Hospital and was inspired and taken care of by a team of caring healthcare workers. They taught me to have a purpose in life, to have a habit of doing exercises and to learn to change, such as changing our attitude or changing our tone and sayings. COPE instructors taught me how to relax and reduce fear, and taught me how to set goals such as arranging daily activities so that I could have more momentum in my life.

I did not want to escape the world like an ostrich, nor did I want to lie on bed all day, so I began daily exercises. My first challenge was water therapy. I was a bit scared at the first lesson because I never dipped myself in water, which reached my neck. But I summoned my courage to try, and not long afterwards I could relax myself and enjoyed the movements. I finally overcame this trial!

Thus I learned that our life can be changed, and we should not make any excuses (such as adhering to old habits) to avoid changes. We need to continue to work out in order to see the result.

My second challenge is to make my own gown for my eldest son's wedding. As the day drew near, my neck and shoulders continued to be in pain, but it did not affect my sewing despite the process was rather tiring. The gown gained everyone's applause and their kudos cheered me up. I learned that there must be achievement when we set our goal and strive for it.

### **Changing my speech**

COPE instructors also taught us to be careful with our speech, and avoid saying, "I am in great pain! Oh dear!" A lot of participants were used to saying such words which became their habitual expression telling everyone including oneself that I live in great pain. Saying these words will not help alleviate your pain but will unconsciously magnifies one's pain, and even allow oneself to be bound up in a box. You yourself will be the one who suffer in the end. I seldom said these words in the past, but I complained. My instructors taught us to say things that can keep myself joyful rather than keep complaining. I said to myself, I feel blessed because I am taken care of by my family in the midst of pain.

### **Pain is not everything**

COPE instructors taught me that pain is not all that we have. The more we focus on our pain, the stronger is the pain, the easier we might develop negative thoughts and emotions. I feel upset for a while and said to myself I need to find out the root cause of my pain. I need to deal with it. But I cannot find a way out after so many trials and attempts that were nerve-wrecking and time-consuming. COPE programme helped me learn to stop: stop complaining, stop looking for a way out, and accept that my pain is not curable, and we have to learn to live with pain. In the process, I learned to move on and be open-minded. I learn to set a goal to move forward. I remember what my instructors said, "You can still eat even when one tooth falls away. When your feet are in pain, you still have your eyes, hands and brain to work for you and be a useful person." I prepared myself psychologically that if I have to use wheelchair one day, I can still function and will not give up easily.

I now can describe myself as a free bird and I live a good life. I will set some targets each day and plan what to do, such as meeting friends, singing, rehearsing, volunteering, shopping and dining. Or I will stay at home and do some exercises, do some craftwork and learn new things so as to find joy in our everyday living. My pain hasn't gone away till now, but this is not what I focused on. I already forgot its existence, and I can be engaged with what I enjoy most.

## Response from COPE instructor

Mr Tse, occupational therapist

The “occupation” as in occupational therapy refers to a meaningful life. Occupational therapists help patients in three main areas: self management, work and leisure so as to empower patients and help them reintegrate into their everyday living. Our aim is to help them choose a meaningful life and to enjoy the pleasures of life.

As an occupational therapist, I am really happy to see Yuk-fong describe herself as a free, ever-living bird. In China, the ever-living bird is called phoenix, which means rebirth in fire. Though Yuk-fong lives in a burning situation, she describes herself as a free bird and lives a good life. She can put classroom knowledge into practical use and learn to rearrange her daily routine so as to plan her activities positively and explore new pleasures and meaning in life.

1. start with simplicity

In a lesson about utilizing our free time, I encouraged Yuk-fong to work on a craftwork that is easy, interesting but pose some challenge to our physical strength and endurance. In this way one can learn how to find joy in leisure activities. She chose to make a bracelet which is not without challenge in the process. She felt muscle tension and pain in her neck and shoulders, but her self confidence and sense of satisfaction increased when she saw the final product. She then tried to work on other more challenging craftwork. Now she can make her own gown again and can even make leather jacket and leather handbag.

2. Learn how to live with pain

Yuk-fong will add in some adjustment techniques in planning activities. Adjustment does not mean cessation or rest, but slower pace, change of posture, some light and stretching exercises etc. Whenever she felt pain, she tried using adjustment methods coupled with the application of ergonomics so that she could finish her tasks easily. She also used some energy-saving principles in activities such as the use of accessories (e.g. an electric mop) to finish her chores.

3. Accept the present self as a starting point

Yuk-fong learned to move on and accept her limitations, i.e. not to compare herself with others but to start from a realistic condition according to her own ability. In the process of sewing garments, she used to feel burnt out after sewing for forty minutes. Now she learned to use eighty percent of forty minutes (i.e. thirty-two minutes) as a starting point, after which she would make some adjustments. She then increased the duration every two to three days to enhance her skills and capability. After each task, she then evaluated her skills and effectiveness to see if there is room for improvement. She put these into record for future reference. Yuk Fong realized that after using the above routine, she could now work for two hours without any problem.

4. Keep positive and maintain healthy habits

Yuk-fong learned to "stop" – stop complaining, but stay positive and keep up her spirits to live with pain. In addition, she maintained a habit of regular and balanced diet as well as regular sleep pattern.

5. Set short term and long term goals

Yuk Fong set a number of realistic and feasible short term and long term goals. She gradually achieved a number of targets through perseverance. These include completing a babysitting course, Chinese dance class, Cantonese opera class and volunteering work.

Although pain never left Yuk-fong, she did not grumble anymore. She lives like a free bird and plan her daily routine to find the pleasures of life. Let's hope that all pain patients can learn from Yuk-fong and rearrange their everyday life. They can choose to live a meaningful life and enjoy the pleasures of life.

## **Response from Holistic Care Team**

Ms Fok Sum

Life is full of ups and downs which are a valuable and important experience. Yuk-fong's experience is a process of experience, reflection and learning.

She could not find the treatment after many consultations, but she enjoyed the company with her family. Her elder sister and brother-in-law committed suicide and left an indelible mark in her nephew's life. But such experience became a reminder for her family. She suddenly realized in a painful experience that pain would not take her life, and she understood one thing: if medicine is not effective, why rush to hospital for medication? Her husband said, "You survived all the major illnesses in the past." She discovered her ever-living spirit in herself. She could rise to the challenge despite the challenges she faced in the past. Thus she reignited a positive attitude and regained her determination and momentum in life. She joined COPE programme and learned how to set targets and get involved in exercises, hobbies, and learned to adjust her attitude and expectations. Yuk-fong knows that the pain management centre is not a magic stick. She transformed her knowledge into habits and overcame the pain after persistent efforts.

Yuk-fong believed that the support from her husband was of utmost importance. Fighting a battle alone can be very tiring, but her conviction as a living bird is conducive towards overcoming the pain. Yuk-fong described herself as a small bird that flies out of the bondage of pain. It flutters around and enjoys the freedom and happiness while in pain.

### **I must survive**

Wan Na, aged over sixty, is widowed more than twenty years ago and was left with two children. She once lived in Canada. In a corporate restructuring in 2005, she was forced to step down from her much loved job. She was frustrated since that incident, and became depressed afterwards. She shifted to be an insurance agent in order to make a living. But she did not yield satisfying results three years into the industry, and felt her health was not as good as before. She decided to return to Hong Kong for retirement. She felt pain in her lower right limb since 2010, and her conditions were not so stable. She was worried that she might become disabled after a year of pain. She joined COPE programme in order to learn to take care of herself when her daughter left home after marriage.

#### **When pain suddenly struck**

In 2010 I suddenly felt immobilized when I was about to get up. It took me much efforts in order to get up from bed, and my lumbar was in great pain. I was very scared and did not know what caused the pain. What I knew was that I felt pain while standing, sitting or walking. I kept calling my friends to seek their advice. A friend of mine referred me to have Chinese massage, and I used my umbrella as a walking stick to go for treatment. I felt great difficulty boarding or alighting the bus. During the Chinese massage treatment, my muscles were hardly pressed, causing great pain as well. I asked to stop the treatment for fear of hurting my affected areas further.

Another friend recommended acupuncture to me, so I tried with hope. Upon examination, the acupuncturist suggested that the pain might be sciatica, so he put needles on my affected areas. Over twenty needles were placed, and five treatments were done during the course. But even such did not yield results after medication. I felt helpless again. The doctor suggested me undergo x-ray examination. After reading the reports, he said that I have bone spurs and one side of my lumbar was bent. He suggested that the treatment would take time, and that I should increase the number of treatments, so I continued with acupuncture. But my conditions were not stable and the pain extended to hip, thighs and legs.

#### **Self-closure**

The pain had greatly affected my everyday life. Things which I took for granted, including tasks that could be done easily now required great efforts. These include teeth brushing, face washing, toileting etc. I even made a mess while squeezing the toothpaste. I cannot lower my head as this could cause pain. I need to hold up my bowl and chopsticks during meals. I could not complete the house chores and need to cancel appointments with friends. There was a time when I took a long time and much energy in reaching a meeting place to meet my friend who came home from afar. I need to grab something to move myself forward whether I was sitting, getting up or going to the toilet. My friends were shocked at my worsening conditions. I hate exposing my weakness to others, and felt rather embarrassing.

I am not unfamiliar with pain, as I was already suffering from joint pains and gout. The pain went away two to three days after taking painkillers. But this pain that came from nowhere made me feel very scared. I knew nothing about this pain, and nobody could tell me anything about its recovery. I felt that pain was going to overwhelm my whole body, and I said to myself, “Will my pain continue to worsen? Will I become disabled? What should I do?” When I had bad mood, I felt myself useless, neglected, and sad memories would then flash through my mind. I became a single mother when my husband died of accident some twenty years ago. I decided to move to Canada for the future of my children and for fulfilling my husband’s will. I kept working hard in a foreign land, which led to lack of communication with my children. I neglected their needs during their formative years, and they became indifferent to me. This is what made me sad and disappointed. These negative thoughts kept occupying my mind, and sometimes I would delve into such thoughts and lost interest in everything. I could not sleep well at night and my life was turned upside down. I lived a disordered life, and I felt I lacked a sharp mind.

In the past, I would persevere no matter what happened. Facing the sudden death of my husband, I moved to a foreign place and raised up my children in his absence. I could persevere in the past, but such stamina was disappearing over the passage of time without myself knowing it. My present self was overwhelmed with sorrow, and I would easily burst into tears after learning of bad news from TV or radio. My tears ran down when I saw that I was on my own without being cared for and understood.

### **Heaven opened a door for me**

The doctor had some doubts over the pain I described to him, and noticed that I had emotional problems. He referred me to see the social worker. After joining a few seminars organized by the social worker, I felt that my knots were still there, and these questions kept haunting me. I often switched on the television and radio to create some noise at home. I came across a programme that talked about the scheme for chronic pain patients and its relevant treatment, during which the audience could call in with questions. When I heard what the doctor mentioned of the programme, I suddenly felt an urge to call the radio programme in a hope to find a way out.

I called the pain management centre after being referred by the doctor. The nurse then told me that I need to be assessed with a referral letter by the doctor before I could join COPE. I consulted the doctor shortly afterwards, and showed the referral letter to the nurse. After the initial briefing, I still did not receive any offer letters, and I was totally disappointed. I had done everything I could, but why they didn’t take me in. The nurse later arranged me to visit pain department and orthopedic department. I said to myself, “I still had a ray of hope, I can only wait at the moment. “So I continued with the prescription, but the side effects were also numerous, such as drowsiness, memory loss, poor vision and irregular heartbeats.

The pain doctor asked me to stop all medication to be replaced with nerve block injection. It involves some risks which include worsening conditions after injection. I felt uncomfortable and called my children, who were skeptical of the doctor’s suggestions and had reservations about the injection. As I reflected over the matter, I think their hesitation was reasonable – I was on my way to self-management, but if conditions got worse and I could not afford others to take care of me, I

may not even have the ability to take my life. In addition, I could not join COPE after the injection, so I decided to quit.

### **Road to recovery**

For a time my mood was so low that I wanted to take my life. When I thought of my mother, my suicidal thought would disappear. I was not taken care of by many relatives like others, but at least my mother loved me much and never gave up on me. She often encouraged me and said, “When I see that you are unhappy, I also feel sad.” I continued to bear the pain so as to reduce her worries. If I die, my children may be labelled as lacking filial piety. I do not want them to suffer because of me. I continued to bear the pain and to live out of the care a mother has for her children.

When I want to talk to friends, I would call up my friends in Canada as they had been through such pain and understand my suffering. My friends kept comforting me, but I did not have the momentum to break through this wall of pain, until the time when I listened to other patients’ experiences whose pain are more serious than my situation. They could still rise to the challenge and this gives me great encouragement, as if giving me a ray of hope. I then remember my motto – no harm to try. I told myself, I need to help myself. While others are lending me a helping hand, I must make an effort. So I joined COPE with this ray of hope, and I hope that this would make a difference in my life.

After joining COPE, I learned more about the pain and reduced my fear and anxiety. I don’t need to take any painkillers now. The psychologists and nurses in the pain management centre showed me great love and patience and spent a lot of time with me. I felt being loved and I gradually came to my senses from a state of confusion. My thoughts became more positive and not to be in desperation anymore. My pain still continued, but it did not worsen which is satisfying.

## **Response from COPE Instructor**

Ms Marlene Ma

### **Consequences of Pain**

Chronic pain has damaging effects when it continues and when medication does not take effect, leading to low moods and lack of motivation. Since a lot of people have misunderstanding towards this invisible pain, patients often feel helpless and embarrassed. Wan Na is one of these examples. Over the year between her pain first developed and being referred to pain management centre, she kept having negative emotions and thoughts. She felt herself useless, not being cared for, becoming disabled, and even developed feelings of fear, anxiety, frustration, disappointment, and embarrassment etc. As time goes by, these negative emotions and thoughts can become a habitual behaviour which creates difficulty in her everyday life. She would avoid activities in order to reduce pain and anxiety, and she developed anxiety when she thought about the difficulties in life.

### **Desire for a better tomorrow**

Others' sharing at a radio programme triggered her desire to live a better way of life. She then had this thought with expectation and determination: no harm to try! So she took the initiative to enquire about COPE programme details. It is important that the patient takes the initiative to meet the needs during difficult times, because any helpful solutions would need our own initiative in order to make things happen.

Many medical research has shown that self-management techniques is suitable for treating chronic pain. Wan Na avoided exercises, which weakened her muscles and thus affected their endurance. When she did more exercises, her situation improved significantly. In the past, she considered herself becoming disabled when pain struck and she could not see where the future led. Now she is willing to manage herself, practise new way of thinking which helps with her emotions.

Her self-management "remedy" is put into action, and coupled with her clear and realistic goals, she participated in class actively to put knowledge into practice. Today Wan Na looks glowing, she enjoys living and relives her persevering attitude. The key to this change is that she is willing to "remedy" herself. She continues to put the skills and ways of working out into practice, and her situation continues to improve.

Many patients thought that treating pain is the responsibility of doctors, and that their own role is passive. In fact, for a lot of complicated chronic pain cases, patients partner with healthcare professionals. It is only when they are willing to change their habits that they can achieve the anticipated results. Wan Na is a living testimony to that.

## **Response from Holistic Care Team**

Ms Stephanie Wong

When we faced with tough times, we often became too focused on the black spots on the piece of white paper and hope to get rid of them. We spent all our energy on removing the spots but our effort was in vain. We fell into an abyss and lost the opportunity to appreciate the places where there were no black spots.

As Wan Na said, our emotions would affect our health. When we are not happy, our pain struck, when pain got serious our thoughts became more negative, leading us to a dead end in the end. Wan Na was faced with such a situation where her pain constrained her way of living, making her feel useless. Such negative thoughts did not alleviate her pain a bit, but actually worsened her pain. To break this vicious cycle, one has to adjust the focus of life. Wan Na was inspired by others' stories, which gave her the energy to continue the way forward and appreciate the untainted areas in the piece of white paper.

Wan Na persisted with conviction, she was bold in trying new things and was responsible towards her family. These are the good qualities we appreciate. Her positive attitude made her feel satisfying after some progress, despite the fact that the pain was not completely cured. No one could foresee when tough times would come, but we could learn to store tidbits of positive energy into our life bank as a way of preparation, so that we could retrieve such when the need arises.

### **Doctor, thank you for trusting me**

Yiu-chuen, married, is over forty years old working as a furniture mover. Since 2009, he had neck pain after lifting heavy things. He could not return to his work afterwards. Prior to joining COPE programme, he had been suffering from chronic pain for over two years. He hoped that the programme could help improve his physique to do house chores.

#### Casting doubts

My neck was hurt at work around two years ago, and the affected area continued to suffer from a pricking feeling. My right hand later felt a pain similar to the hand of being twisted. After staying in hospital for over ten days, I felt that no painkillers could work, so I simply lay down on bed. I could hardly eat, and the male nurse gave me a thick drinking straw so that I could have congee while lying on bed. This straw could help me more than any of the medicine. As I was in pain, I could not remember the name or the face of the nurse, but I would always remember his concern for me.

After going through MRI examination, the doctor said that there was herniation of the fifth and sixth cervical discs. The discs touched upon the nerves, but the doctor could not explain why this had caused me great pain. I was puzzled by the findings and wonder whether there was problem during the process of MRI scanning. The radiotherapist placed my head in a comfortable position during the scanning process, and I did not feel the pain at that moment. May be this was the reason the scanning result did not show the pressure on the nerves. The doctor said, to my surprise, “You can be discharged, there is nothing that can help you.”

I tried many different therapies after being discharged from hospital. First was physiotherapy, and the physiotherapist helped me on mobilization ability. The effect was acceptable. However, the physiotherapist later changed to another post and his successor said to me after a few treatments, “I think the results have started to level out and you don’t need to come back for treatment anymore.” Next was occupational therapy, and the major purpose of such was to train up my physique. I needed to make efforts in these exercises. There was some progress in the beginning, but as I did more exercises, the pain also increased. I would suffer from great pain if I kept doing the exercises. Later, not only that my physique was not improved – it got worse after such exercises. The occupational therapist said, “You should stop the therapy if there is not much progress.” Thus my occupational therapy sessions also stopped.

When I met the orthopaedic surgeon, I always heard some negative/ unhelpful words, such as “I cannot help you.” “Many people here suffer from herniation of cervical discs, it has been a common problem.” A doctor once asked me to make some movements during the assessment, and he said, “You are normal and can get back to work soon. Don’t idle yourself.” I was in doubt, and I said, “I am in great pain!” He added, “Then work less, but you must work. If you ask me to testify,

I will still say the same. You are not sick.” I started to doubt myself because when the only person who could heal me – doctor – all said that I was well when I was in pain, I asked myself, “Is my pain psychological?” So I decided to neglect the pain and resumed work, but I failed. Not only did my body get worse, but also my mood was getting worse.

### **Turn crisis to opportunity**

These doctors’ responses made me develop a lot of negative thoughts. When I talked about my pain, they did not show empathy. One doctor even said, “You can look for traditional Chinese medicine as a remedy.” When I was hospitalized, the doctor prescribed some anti-depressants to me. He did not explain to me its features, and I felt very drowsy and my heartbeat was rapid after taking these drugs, which I later knew were anti-depressants. I needed pain relief, but I didn’t understand why they gave me anti-depressants. I asked the doctor, but he did not explain and only gave me vitamin pills. The pharmacist, however, told me that these were the latest anti-depressants which were no different from those that I took earlier. I lost trust in doctors after these incidents/experiences.

Finally I was referred to the pain management centre. After a few consultations, the medication was changed and my condition finally stabilized. This was the last time I met Dr Lee, the doctor at the pain management centre. She asked about my mental conditions. By that time I did not have any more expectations, and I did not want to describe to her how much pain I went through and how uncomfortable I felt. I only said, “Every doctor said no one could help me. Your division said this would be the last consultation. I really have no solutions.” But Dr Lee asked about my conditions and I told her my queries and worries in detail. She gave me a detailed examination, and listened to my case patiently. She then referred me to different departments, including occupational therapy, physiotherapy, psychiatric department, clinical psychologists etc for follow up.

When I met the psychiatrist, he asked me one question – did you hate your employer? I immediately said, “No, I hate myself, I hate the doctors!” This answer surprised me as well. Doctor should give me hope, but why did I stand against them? This psychiatrist confirmed that I suffered from a mild to moderate case of depression. After many/ several consultations and drug adjustments, my condition finally stabilized.

### **Being misunderstood**

At the beginning of my illness, my friends and relatives showed me a lot of concern. As time went by, some thought that I was pretending to be sick, not willing to get work, or waiting to be fed by my wife. My wife did not understand my pain, but she still trusted me. It was her family that cast doubts about my pain. Fortunately, even when others were nonchalant about my pain, she still trusted me and said, “Even when he lied to me, I am willing (to be cheated).” My wife did show me great support.

There was a time when I accompanied my wife to the market to buy cabbage and two tomatoes. I carried the vegetables and felt pain before long. I asked her to return home quickly. She was upset at that moment because she did not understand my pain, thinking that I was only throwing tantrums. I did think of whether I should divorce her at that moment. I did not say this out to prevent hurting her. At my most difficult time, I felt hopeless as every doctor said that I was incurable. I was so depressed that at one point I thought of committing suicide. But in the end I did not want to part with my wife. She did not understand me at times, but she still supported me. I later encountered Dr Lee of pain management centre who was so patient in explaining the pain to me and suggested steroid injection at my spine for pain relief, which could be further alleviated through exercises. When I saw that Dr Lee was helping me with all her heart, I did not feel hopeless anymore. I became more positive afterwards.

### **Concern and trust**

I had not been working since this pain occurred. In the first year, I had difficulty doing chores. In the second year, I learned how to avoid pain exacerbation and my conditions gradually stabilized. Upon hospitalization, my company no longer paid my salary or provided any financial support to me. My injury was work related, so the orthopaedic surgeon assessed my case according to the damages I could claim. He felt that I exaggerated the seriousness of my pain in order to claim more compensation. Their attitude and mentality did not take into account the feeling and pain of the patient. I lost my job and was under huge economic pressure, but fortunately I was helped by my previous employer and friends. But, it didn't last long except my wife who was supporting the whole family on her own without any complaints. My younger sister also offered me great help.

Joining the COPE programme let me learn how to cope with pain. My previous doctors could not explain to me the cause of my pain. Some did not agree with my experience and believed that this was psychological. But doctors at the COPE programme could explain to me the cause of chronic pain and let me understand what happened. I did not feel so much fear as the greatest fear came from uncertainty. When I learned about pain, I felt this was just pain which was nothing but pain. I could accept the pain and could cope with it. Now I no longer fear pain as I know how to adjust, relax and cope with it. But knowledge is not the most important thing, as what is most important is the concern and trust by these healthcare workers, who have showed me more care than I would myself. This becomes a confidence boost to my long road to recovery. I will work hard to face my life so as not to let the whole team down.

## Response from COPE instructor

Dr Sandy Lee

For a long time, traditional medicine emphasised on the anatomy, physiology, biochemistry of the human body in treating patients, but neglected the importance of the patients' psychological and social aspects. These factors often affected the behaviour, response and treatment methods of patients. Nowadays healthcare workers suggested the use biopsychosocial model to manage patients, a philosophy known as patient-oriented culture. Good communication techniques become an indispensable tool for healthcare workers. The dissatisfaction of Yiu-chuen and his hostile thoughts towards healthcare workers reflected the adverse impact that the lack of communication could bring. Thus, healthcare workers need to constantly reflect and improve on their verbal and nonverbal communication skills. Besides, they should pay attention to their attitude towards patients:

1. Active listening

Listening is a basic technique. It is not easy to be a good listener as this may be affected by a number of factors, such as insufficient time during consultation, environmental noise, inexperienced healthcare staff and prejudice of healthcare workers etc. So healthcare workers should listen to the patients and understand the real meaning behind words.

2. Empathy

We should put ourselves in the shoes of patients and understand their feelings and pain. If doctors respect and care for the patient, make them feel accepted, trusted etc. that is empathy. Empathy is different from sympathy, because if there is sympathy, our attitude would be filled with prejudice or criticism. We should have empathy towards our patients and understand their feelings.

3. Proper sensitivity

Healthcare professionals should be sensitive to the patients' abnormal or inappropriate language or behaviour and carry out in-depth discussion with patients to understand the reasons behind. We should apply professional knowledge and expertise to these cases and guide patients in solving their problems. If the cases are complicated and are beyond our capability, healthcare workers should refer patients to suitable specialists for assessment and follow-up treatments so as to prevent the deterioration of problems.

Good communication is very important, as it helps healthcare workers to understand the patients' conditions which in turn help in making the right diagnosis, thus reducing chances of misunderstandings and conflicts. In addition, communication can help build trusting relationship between patients and healthcare workers, enhance the patients' confidence and cooperativeness in the treatment process as well as their satisfaction towards treatment. Communication skills cannot be learned overnight but would be enriched through training,

practice and self-reflection, which will finally see the improvement of their communication skills, thus yielding the best treatment effect.

NICHE

## **Response from Holistic Care Team**

Dr Andrew Luk

Yiu-chuen quit his job due to pain. He felt a loss of social function and was misunderstood as lazy or pretending to be unwell. Some even thought that he exaggerated his illness in order to gain sympathy or claim better compensation. Understandably, he felt uncomfortable towards these claims. As a healthcare professional, we should listen to patients' voices to avoid being deemed as indifference to their feelings. But it takes years of experience before we know how to explain to them their conditions. Healthcare professionals can learn and improve by listening to their responses. Treatment for some difficult diseases may not yield obvious results, but if healthcare professionals are willing to lend an empathic sympathetic ear and explain their situation in more detail, this will give more comfort and hope to patients.

NICHE

### **Correctly Step by Step**

Ken is a car maintenance worker of over thirty years of age. He is married with two children. He lives with his wife and his mother. Since the slippery accident in 2005, he suffered from back pain after falling on his back. He hoped to enhance his physique by joining COPE programme, so that he no longer needs a walking stick. He had this chronic pain for over 2 years prior to joining COPE.

I did not feel such pain immediately after the injury, but later it got worse. I did not know why I felt this pain, when my feet touched the ground, I would feel pain and numb, I did not want to move. I need a walking stick in walking. I felt bad that I need a walking stick to assist my walking while young.

It does not feel good to be a patient, even worse is the doctor's comments after diagnosis, "I cannot find any issue from X ray films. "People close to me did not trust me, rather, they asked, "Why didn't you go to work? It is not a big issue." I felt especially down and became negative in my thoughts. I gradually lost my self-control and cannot sleep well at night.

I tried other ways in the days to come. I tried bone-setting, Chinese medicine, acupuncture etc., but did not yield results. All healthcare workers said that I had no big issue, some even thought that I was lying and pretended to be sick. I once could not move due to pain and need to go to Accident & Emergency Department. But the doctor did not believe that my pain was unbearable, I kept asking myself, "Why such a pain? Does the problem come from within myself? I really don't know." Such circumstances made me feel disillusioned and felt that others were talking behind my back. I need to be referred to psychiatrists and I was diagnosed with depression.

I cannot sleep well during that time, and I lost my appetite and ability to work. But the doctor still said that I had no big issue. Insurance company also called to check my status from time to time, which was really a nuisance. I felt very fearful as nobody could help me. I felt angry when I was disturbed, and I often carried a knife with me while out and about, thinking to myself, "If you disturb me again, I will stab you!" I tried to change to be an office worker in my previous employer, but I felt pain after sitting for too long. I also felt that the colleagues at the company were united in standing against me, so I gave up the job.

I was then staying with my parents, wife and children. As I was struggling daily, my father was diagnosed with cancer. He was in distress during the treatment period. One time, as I was left with my father when my mother was out, my father said, "I need water!" He could not get up from bed and needed me to lift him up. But I cannot help due to my pain which made me feel a sense of guilt. My father was sent to hospital later, but I could not take care of him, making me feel sad and embarrassed.

My daughter was only slightly over two years old and my son four years old when my injury happened. They were all studying in a kindergarten. I could not control my temper at those times and would beat them up. I felt regretful after doing this. There was a time when my daughter fell to the ground while biking, hurting her knees. I could not lift her up, then a passer-by said, "Why didn't you lift your daughter up when you are so young. Ask somebody to help you!" I felt pitiful after hearing this, and not only did I become dissatisfied with myself, I hated myself, and I felt that all the world including my wife did not trust me. I could not sleep well every night, and I would get up from bed at night. My wife went to work in the morning, so I decided to sleep separately so as not to disturb her when I switched on the light.

### **Reborn through faith**

I was referred by Prince of Wales Hospital to the pain management centre at Alice Ho Miu Ling Nethersole Hospital and joined the COPE programme. I felt I changed a lot after joining the programme. Ms Ma, who often contacted me, showed her concern to me most. Mr Wong also trusted me a lot. When I told them my conditions, they all trusted me and accepted me. They also explained to me what caused the pain. At a time when I lost faith in everything, when even my previous colleagues who had known me for over a decade did not trust me, when my friends and doctors did not trust me, Ms Ma and Mr Wong did trust me. Their trust helped me restore confidence, and I started to have the momentum to try to change. I said to myself, "Since they are willing to help me, why not try it? After all, I did not want to stay like this for the rest of my life." In addition, I need to take care of my mother, and I did not want others to say to my children, "You have a father who relied on a walking stick."

Ms Ma and Mr Wong taught me different ways of alleviating pain, such as how to walk, how to adjust pain etc. I would then try to apply these to practical use. Mr Wong is willing to listen to my complaints and comfort me. For a time I carried a knife when I went out. After his consultation, I handed the knife to him. My pain did not reduce during the treatment process, and I started to become sceptical. I said to myself, "Oh, why I still suffer from so much pain without results? There is no progress at all. I felt even more pain after listening to your instructions. I think I don't need to be serious about that." I later realized that I did not use the right way as I was too aggressive. I wanted to take the short cut and thought that I would recover quickly after walking more. After listening to their instruction, I started to learn slowly and grasp certain key points to work on. I need a walking stick to assist my walking in the beginning, later I used an umbrella, and later I did not use any tool to walk. My children saw that I did not rely on a stick were more willing to hang out with me. My confidence gradually built up, which gave me further determination not to use the stick.

Now, I understand that I need to work on my own pain, including relaxing myself, not to rely on medicine etc. I thank my family for their endless support for me. My children used to avoid me, but now they want to be with me. They would invite me to their sports day at school, and said, "Dad, you must come to support us!"

## **Response from COPE instructor**

Mr Leo Cheung, Physiotherapist

It is no mean feat for chronic pain patients to break through their physical limitations. To Ken who has been suffering from over two years of pain, this is a big challenge. The suffering brought about by back pain not only includes the pain but also reduced physique. Ken used to be a vehicle technician and was as strong as steel. Now he has to rely on a walking stick to assist him in all daily activities. This affected his relationship with family and friends and even lead to his depression.

In the initial stage when Ken joined COPE, his pain increased while doing rehabilitation exercises. His mind was filled with doubts and would like to give up. His response is common, and as many pain patients had faced and experienced such a stage.

During the COPE programme, we suggest patients use pacing skill to enhance their physique. First, patients start with an exercise level which can be coped with by an individual. The workout time will gradually increase in frequency and duration. One has to work on each exercise for several days to give enough time for the body to adjust. As the body has been accustomed to the amount of exercise, one should gradually increase the duration and frequency of exercise according to a pre-set goal.

When one experiences great pain, he or she should not stop exercising, but reduce the exercise level by half or by one-third. When the pain reduces, patients can gradually increase exercise or restore to the original exercise level.

Take Ken as an example, his purpose is to walk without the use of walking stick. Using the pacing skill, Ken has set a goal and expects a time length where he does not need the help of a walking stick. He then works out according to this goal. When the goal was reached, he will continue to challenge himself and lengthen the time he does not use a walking stick. If he continues to do this step by step, he will see progress.

## **Response from Holistic Caring Team**

Dr Andrew Luk

What Ken felt most painful is not his physical pain, the loss of his job, lack of mobility and earning power and reduced self-control, but distrust and the feeling of unacceptance by his loved ones. The loss of trust impact on his dignity and self-confidence, which made him lack the motive to recover. When he described his pain to healthcare workers, their lack of understanding and trust made him feel even more disappointed. Regardless of the x-ray examination results and the diagnosis given by doctors, his feeling of pain was real to him. When he was listened to, cared for and accepted by healthcare workers, his confidence was restored. He was willing to take up new challenges and learn to live with pain. Ken continued to progress and later he did not need any painkillers and walking stick, and can interact better with his children. His confidence is rebuilt and does not feel depressed anymore.

NICHE

### **Roly-Poly**

Fei Long, aged over fifty, is married with a 7 year-old daughter. He used to be a tour guide. He suffered from stroke three and a half years ago. He was recovering well initially and did not require any walking aid. However, half of his body was later paralysed and he felt increasingly burning pain which affected his emotions and everyday life. He joined COPE in a hope to adjust his mindset to overcome the negative impact brought about by the pain so that he can reintegrate into the society.

#### **Complications of stroke**

About three and a half years ago I started to feel numb all over my body. My brain then suffered from haemorrhage. I thought that having a stroke is a minor illness and did not treat it with care, thinking that it will be healed in two months and I can resume my work later. I was positive about the recovery initially. But as time passed, I started to feel not quite right seeing that the recovery process was slow. I tried many different therapies including acupuncture and physiotherapy. The therapists were very helpful and were able to slot me in appointments when other patients did not turn up. I was on a wheelchair when discharged from hospital. I live in a village house with flights of stairs, as such I faced different limitations in my everyday life. In spite of this, I still continued with physiotherapy and occupational therapy. I also started to practise walking and increased the length of walking distance gradually. Six months later, conditions gradually improved, and I can walk on my own. But I cannot return to my original post due to reduced physique. I still got some jobs relating to tourism in Japan occasionally, but my income was significantly reduced. The tsunami that recently took place in Japan greatly affected their tourism industry and economic environment, and I was forced to leave this job.

#### **Live with pain, struggle with pain**

I am a tough person and I never complain even in sickness. My only hope is to deal with the situation quickly. After the stroke, I just wanted to focus on doing exercises and training up my physique. I was a tour guide and have been busy all my life. I seldom celebrate festivals with my family. Even at the Chinese New Year, I would have to leave immediately after the New Year dinner. My life was too busy previously, and this illness reminded me to stop and rest in my second half of my life, so that I can set off a new journey and fight a good fight again.

But despite my strong character, my emotions will still be affected when my physical conditions were really bad. I easily lost temper and often fired off people, even my family members are no exception. My relationship with them worsened. I love my youngest daughter very much, but I cannot hold back from scolding her when I was teaching her. I would feel very guilty after scolding her and would feel heartache for three to four days. On one hand my income reduced, but on the other hand my wife did not know how to manage finances prudently. All these added to my worries

over my household finances. I often slept a lot, thinking that I could sleep off it and forget everything. But when I woke up, I need to face the numb feeling over the whole body again, which was unbearable and irritable. In the end, I chose to live with it, and when the numb feeling arises, I will say, "Oh, it hurts me again." I will focus on my work and that irritable feeling will seem to disappear temporarily.

### **Never give up**

I wonder whether this strong character is inborn or developed afterwards. I only know that I have been through many ups and downs in my life. My father came to Hong Kong due to political reasons, and my mother brought me along to find my father, only to find that he had an affair with another woman. My mother and I then illegally immigrated to Taiwan, but after many twists and turns we reunited with my father in Hong Kong. I was often bullied due to the lack of parental care and protection, be it in Hong Kong or Taiwan. I did not speak Cantonese nor English when I first arrived Hong Kong, and I was labelled as "You dead Taiwan boy!" I did not give up and worked my way up to get good results in examinations. I later studied in Japan and had three marriages in Taiwan, Japan and Hong Kong respectively. I was once addicted to drinking after suffering from failed marriages, jobs and unhappy life. I drunk day and night without stop and did not want to remember anything. I just wanted to drink till I die.

Though I was subjected to various limitations with this illness, I never thought about committing suicide. I know that any kind of suicidal attempt would be very stupid and painful. My emotions were low at the beginning of the pain. When my pain was still the same after the two month golden recovery period suggested by the doctor, I turned from optimistic to feeling frustrated. During my desperate moment, I asked myself, "What should I do?" I was disappointed but I never lost my willpower. I said to myself, "If this road was not open, then take another route." I often encouraged myself by saying, "Nearly there! Nearly there!" I persisted with my conviction, and I kept moving on. I hoped that I will be recovered one day. When I learn that the situation is irreversible, I would change my plan and think of another way out. My strong character is my driving force.

Joining COPE programme is a turning point in my life. The hospital clearly stated that the programme will not make my pain or numbness go away. I will learn how to live with pain. So I had prepared myself psychologically. When I learned about pain during the programme, I met a group of companions who would keep contact after class. We would have reunion from time to time just like a family and we were very pleased about that.

When sometimes depression and disappointment strike, I may still think of negative thoughts. I will talk to my friends when this happens. The second half of my life is not my own choice, but I have a different life experience. I used to be impatient and bad-tempered, but I slowed down after the illness and have time and space to reflect. I learn to be less impatient now.

## **Response from Holistic Care Team**

Ms Stephanie Wong

Mencius once said, “When heaven is about to place a great responsibility on a man, it always first frustrates his spirit and will, exhausts his muscles and bones, exposes him to starvation and poverty, harasses him by troubles and setbacks so as to stimulate his mind, toughen his nature and enhance his abilities.” Not everyone can endure suffering, but such suffering foreshadows a big mission to be placed on him. Everyone will face tough times which are unavoidable. But we can choose our attitude during tough times. A terminal cancer patient went to see the doctor with a different attitude. The doctor was very surprised by her positive attitude despite the fact that her conditions had not improved. She said, “I am very happy today because I have decided to make myself happy.” It is a choice to be happy or unhappy. The decision to face tough times with whatever attitude lies in us. Fei Long’s story taught us that we could face tough times with a positive attitude. When tough times passed, we could learn something out of it, and we will be able to solve problems when we face tough times again. It seems we do not have a choice during tough times, but in fact a choice is hidden.

## **Response from chronic pain patient**

When we suffer from chronic pain, do you

1. Understand your personality?
2. What difficulties did you go through after the chronic pain?
3. How can your personality help you face difficulties?

### **Love is the driving force**

Josephine, aged forty, is married with two sons. She works as a librarian assistant. She was injured at work and has been suffering from back pain ever since, thus affecting her work. The reason for her joining COPE programme is to pick up the activities that she gave up after pain struck, such as hiking and family activities. Josephine has been suffering from pain for over three years before joining COPE programme.

#### **Happy family**

I have a happy family with six people, including my husband, father in law, mother in law and two sons. My husband needs to ply between Hong Kong and China for work, and sometimes he has to stay overnight in Mainland. I work as a librarian assistant and rely on the help of my father in law and mother in law to take care of my two sons who study in primary school and kindergarten respectively. Our relationship is harmonious and we will take care of each other. During holidays I will become the event organizer and arrange various programmes for our family - sometimes ball games, sometimes going to outlying islands for a break. If there is a long vacation, we may travel to other countries. I enjoy cooking and will organize food parties at home to demonstrate my cooking skills while at the same time enjoy the happy reunion time. During festive seasons I will arrange with relatives to dine out in restaurants for a big reunion. Though life is busy, we enjoy our life.

My husband and I have been married for eighteen years and we work hard in building our home. We work hard but also enjoy our family time. We take great care in maintaining our relationship and will arrange dating time to talk about anything. We have endless topics and we are close to each other's heart, as close as chopsticks.

#### **Work injury**

One day in 2003 I felt back pain after moving several boxes of books in the morning. In the afternoon, I continued to move books to the shelves as usual. After a few rounds, my back was in pain, but I could still continue to work. My back became heavy and later I could not move a bit. My colleagues saw that I looked pale with a twisted face, and asked about my condition. I realized that I could not continue any longer. I wanted to take leave and see the doctor, but my supervisor asked me to finish the work on hand before departure because there was no one to take up my work. I asked my husband to accompany me to nearby Accident & Emergency Department because of my back pain.

After the diagnosis, the doctor said that my back was normal according to x-ray examination. I could resume work after resting for a week. But since then my back pain never went away, and I began to suffer from chronic pain.

In the first six months, I had to visit government outpatient clinic every other two to three days to extend my sick leave. My friends referred various doctors to me after knowing that my back was in pain. I tried painkillers, antibiotics, sovereign remedy, Chinese massage, acupuncture etc. I often took taxi to seek treatments while in pain, and I would go anywhere to seek treatments. Sometimes I went from Tsuen Wan to Wan Chai just to try to find a doctor who can cure my pain. After more than three years of diagnosis and examinations, the MRI scan showed that the root cause of my pain was lumbar disc herniation which touched upon nerves.

### **Going crazy**

Other than the physical pain, I also felt exhausted and tired after each trip to the library to apply for sick leave while in pain. I had to commute a long way to the library while at the same time I need to communicate with my boss about my illness. I need this job in order to support my family, so however painful, I still have to complete all necessary procedures. My boss later allowed me to fax my sick leave application form through a nearby library, but I still have to call my boss and I would hear some nasty words each time. I felt distrusted and misunderstood, so my mood would be particularly low before I apply for sick leave. I seldom contact my colleagues due to negative emotions. Only my partnering colleague who worked with me on the day of injury called me up and encouraged me at times.

As my back pain was getting worse and affected my whole body's movements, I gradually find it difficult to walk and to go to bed. I could not sleep and may be awoken by pain during sleep. When my limbs were pressed, I could not move my body but had to wake up my husband so that he could turn round his body. Later I suffer from insomnia, initially at night and later I could not sleep at night or during the day. I could not go to work, cook, do chores, take care of kids and need others' help in changing clothes, taking shower and bathing, which I finish with great pain. I feel that I am a useless person who is gradually swallowed up by pain. During family gatherings in festive seasons, I could join while in pain, but I could not sit for long, not even with the help of waistband. I need to get up and walk every ten to fifteen minutes. My family is used to my way of sitting up and down, but I feel embarrassed and frustrated and painful.

I was under huge pressure from my boss, work and family life, and these pressures were more than I can bear. My emotions became unstable and I would suddenly weep and suddenly lost tantrums. My family members became an outlet for my frustrations. When emotions burst, they become uncontrollable. I thought about committing suicide twice or thrice in order to escape the pain and suffering. But I dropped the idea because of my love for my husband and children.

### **Three generations of love**

When I calmed down, I realized that I am unreasonable which made my family suffer and made me feel guilty. My family has to suffer for my pain, but they accepted me and loved me. When I could not take care of my son, my father-in-law and mother-in-law are willing to take up my role without whining. They always sent me regards when I was in pain and angry. My husband is a really good husband who would always understand me and listens to my needs patiently regardless of my temper or emotions. He would then comfort me and encourage me. He once asked me to put aside my work because my health is most important. He suggested that we should sell our mortgage free property to cover the medical expenses. My two sons were understanding and would rub ointment on my back when pain struck. When my mood is low, my eldest son will send me tasty snacks. My family has such great love for me, but I would ignore them or even throw tantrums at them when my mood is low. They had to bear my attitude and temper, and were saddened because of me. If this situation continued, our family relationship might collapse like the domino effect. I did not want to see this happen.

### **Love is the driving force**

One day, my youngest son said to me, “Mom, we have not been out for a long time.” This is a wake-up call to me. My pain made me become self-centred and neglect their needs. A lively family suddenly lost its momentum. I said to myself, “I must live like a normal person from now on. I must walk out of this abyss. I must return to my way of living before.”

I know that my family loves me very much, and I love them as well. I often love them more than I love myself, that’s why I would take time to arrange family activities and schedule. I must change for the sake of my family. I need to move on and make the greatest efforts in returning to a normal way of life like before. My family’s love gave me courage and motivation. I was determined to walk out of darkness and I started to join different courses and learn new things.

After joining COPE programme, I am thankful for the care and guidance by the healthcare workers. I learned to redefine pain, and how to live with pain. Though pain still lives in my everyday life, it will not master my life. I hate such an abnormal life and did not want to continue this kind of life. My biggest motivation comes from my will to change myself. I often reminded myself not to give up. The programme led me to set targets such as returning to a normal way of life, then to adjust and to gradually resume my previous hobbies. These will be combined with exercises in order to apply the knowledge into everyday life and become a habit.

In addition, I joined a psychology course and understood what it means by “awaken through loss, and positive because of love.” The course enhances my knowledge of myself and of others. In a course on interpersonal relationship, I learned how to work with colleagues and the art to honestly express myself, to focus on the subject but not on the people and to show appreciation.

### **Picking up hobbies**

This turned a new chapter in my life. I felt more positive and I could control myself despite mood swings. I can still go anywhere despite at a slower pace. I used to be afraid of taking the minibus or the bus as I have difficulty boarding or alighting the vehicle, but I can cope with it now. I had not entered the kitchen for two to three years. Now I will use the kitchen for cooking if my conditions allow me. I gradually resumed my work and I changed to a location near my place. I worked half a day each day in the beginning. The working time gradually lengthened to full-time employment. I felt tired after work, but this is manageable.

In addition, I started volunteering, which is like killing two birds with one stone. On the one hand I can help others which made me happy, on the other hand I can put aside my pain when I focused on the volunteering work. Knowing that my physique was weakened, my volunteering partner would ask me to do less labour work but focus more time on coordination, which is my strength. I even brought along my elder sister, my sons and husband to join volunteering service. It is more blessed to give than to receive. I was able to enjoy my family life at the same time, what a double blessing!

### **Response from Josephine**

My gratitude goes to the doctors, nurses and physiotherapists at Alice Ho Miu Ling Nethersole Hospital pain management centre whose efforts and persistence in carrying out this mission gives new life to a lot of pain patients and their family members. In addition, I am thankful for the opportunity to share my story here. Our biggest enemy in life is our self. I wish to offer my sincerest blessings to you and I hope that all patients will recover soon. Tomorrow will be another day.

### **Response from readers**

1. How is your relationship with your family members?
2. What is your motivation at this stage in life?
3. How can your motivation help you face tough times?

NICHE

### **The power of faith**

Chun, aged over forty, married, as a housewife. Since 2001, she started to feel neck pain and back pain without any traumatic experience. She looked for various therapies and doctors to alleviate her pain, including acupuncture, Chinese massage, orthopaedic surgeon and psychiatrist, whom she once placed hopes on. Before joining COPE, she has already sensed that her five-year-long back and neck pain may become a part of her life. She hopes to reduce her fear and anxiety towards movements through this course.

#### **Long term struggle**

I nearly had nervous breakdown during the period from 2001 when pain first struck to 2003. It was the most helpless and painful moment in my life. I could not sit or walk and I kept asking myself, “Why has this happened?” I need to stop and rest every ten steps, not to mention after lifting heavy objects and climbing five steps of stairs. I was awoken by pain in the middle of the night and I could not fall to sleep easily. I even felt pain in my chest and the pain was indescribable.

At first, I thought I could find a good doctor who can cure my pain and get healed. But it was not as simple as that. I consulted the orthopaedic surgeon at first and did not see any results after taking medicine. I then consulted psychiatrist and I felt better after medication, but I still was in great pain. After resignation, I stayed at home all day and could not do any chores. I fell asleep often and I was in a state of confusion and liked to stick to my bed. I felt I was useless, and I easily threw tantrums. My husband became an outlet for my temper. Fortunately, he tolerated my temper and though he did not know how to comfort me, he would urge me to quickly see the doctor after seeing my painful face when he returned home from work. I thought to myself, “A normal person has to take care of such a negative person as myself who always whined about the pain and said that I was going to die. How will he be happy? I was in pain, but I should not burden others. He could not sleep and were in low spirits at work. He was worried about me. I felt that I was a big burden to him.” In order to reduce his workload, I stayed with my elder sister or mother for a period of time so that they could take care of me.

#### **The power of faith**

Christian faith became my strength at my most helpless difficult time. I picked up the Bible which I had put aside for a long time. During the most painful moments, I read the Bible and came across this verse, “It is precious when a person learns happiness while in pain.” This reminded me that we should learn to be joyful in pain, and cherish what we have in order to have true happiness. I tried to change my thoughts so as not to be controlled by the pain. My faith became the cornerstone of my life, and I reckoned that pain is an inevitable experience. As I look back, I have hands and feet, I can talk as well. Isn't this a blessing? We should not think that we are the most pitiful person on earth, as there are many more who are less fortunate than us. Other than reading the Bible, I listen to sermon on Saturdays which touched me and inspired me each

time. I also join cell group activities and shared my experience with others, who also gave me support and encouragement.

### **Benefits of the programme**

After living in pain for seven to eight years, I was referred by psychologist to pain management centre. I joined the COPE programme and from that I realized that I am the one who could truly help myself. During the programme I learned to think positively, be alert to negative thoughts etc. We often are inclined to think negatively when something happened, rather than thinking of the positive side. This might become a vicious cycle. On the contrary, the happier one became, we would be less stubborn and would let go of certain things. We would then see the world as a much better place. In conclusion, I learned two life principles during the programme. First, be positive in our thinking, because patients tend to be negative in their thinking while in pain and suffering. They do not think positively. It is not easy, but I will try hard to learn. Secondly, we need to do more exercises. Before joining COPE and in the beginning of the programme, I used to have a psychological barrier, thinking that the body will be in much pain after exercises. I doubt whether I will hurt myself. But in fact, I will feel pain without doing anything, so should I continue to move about as usual? Or should I stop all activities? Now I learn to adjust, to work and rest after listening to instructors' advice. I won't run or stand for nearly two hours without stop as it happened in the past. I will do chores in the kitchen, such as washing dishes, and I will wash half of the dishes, and then stop and rest for a while, watch television before washing the remaining dishes.

During the rehabilitation process, I was assisted by the healthcare team as well as my family members. My husband, mother and elder sister cared for me and encouraged me, for which I am thankful. My mother is in her old age and could not really help much, but she would express concern by saying to me, "You should move more, do more exercises." I could see that she did care for me and worry about me, which is a form of encouragement for me. I now can cook for my husband, as I can overcome my pain to shop in the market, while at the same time I want to be a good wife and take care of my husband. I continue to attend Sunday worship and cell group at church to rely on help from God.

## Response from COPE instructor

Ms. Janet Hui

Chun has been suffering from pain for years and strived to seek treatment. Her pain made her doubt her intrinsic value, and her bitterness was not easily alleviated. Despite the unending support of her family, the troubles brought about by her pain were indescribable.

### 1. Help from God's words

Chun returned to her Christian faith when the pain began. She got relieved through the Scriptures, and her troubled heart could finally find a resting place. She could see the richness in her life, and was truly set free. Her bodily pain was not fully cured, but God's words gave her strength and became a driving force in her life, giving her joy and peace spiritually. At her most helpless and painful moment, she could experience the truth in God's words, which awakens her soul and gives her the peace and joy that are needed to overcome difficulties and suffering. This is the power of God's words. Jeremiah Chapter 17:7-8 reads,

“But blessed is the one who trusts in the LORD,  
whose confidence is in him.

<sup>8</sup>They will be like a tree planted by the water  
that sends out its roots by the stream.

It does not fear when heat comes;  
its leaves are always green.

It has no worries in a year of drought

and never fails to bear fruit.” A person without God can only rely on himself, and the unstable environment. Our ability is limited, and we are at our wit's end, how can we continue to survive? When we cannot control the environment, what should we do? But those who rely on God can have hope in a desperate situation, because they rely on the almighty God.

### 2. Help from faith community

Faith gave Chun strength through the brothers and sisters at her church. The faith community rendered her support as well as shared her burden. Not only did she find a group of friendly people at the church that made her experience the feeling of love and being loved, but also she was able to share her inner struggles with brothers and sisters honestly as well as matters relating to faith and spirituality. They established a trusting relationship among themselves, so that Chun was able to express her painful experience in front of brothers and sisters. The book of Romans 12:15 said, “Rejoice with those who rejoice; mourn with those who mourn.” When Chun lowered her self defence mechanism, and opened her heart to other Christians who were willing to listen to her, accept her, support her and pray for her, she finally walked out of the darkness and received help from the faith community.

### 3. Help from prayer

When Chun returned to faith, she understood what it means to be a Christian. She admitted her weakness and cried out to God for help. She gained strength through prayers. Philippians 4:6-7

writes, “Do not be anxious about anything, but in every situation, by prayer and petition, with thanksgiving, present your requests to God. And the peace of God, which transcends all understanding, will guard your hearts and your minds in Christ Jesus.” Prayer is related to one’s spiritual and physical health. Prayer is a form of spiritual therapy and could yield therapeutic effects. When one genuinely prays to God and cast his/her pain on God, he/she will feel moved and peaceful, and will gain satisfaction in the spiritual sense. Such satisfaction is beyond words can describe. One will easily have negative thoughts in pain, but we should not listen to these thoughts or allow them to take root. We should remain positive in our thinking even in pain, which is not easy. But the Bible said, “Let us then approach God’s throne of grace with confidence, so that we may receive mercy and find grace to help us in our time of need.” If we rely on God’s help, we should be able to have peace while facing pain and suffering.

Chun strengthened her positive thinking through joining COPE programme. In addition, by doing suitable exercises, she gradually overcame the difficulties brought about by pain. Chun opened a new chapter in life upon completion of programme. She learned to live with pain. With the strength gained through faith and the COPE programme, she learned to cherish what she has and strive to face the future.

## Response from Holistic Care Team

Dr Andrew Luk

Chun has been suffering from pain for years. Thankfully, her family gave her unending support, and she was helped by her Christian faith. Upon Chun's training at the COPE programme, her positive thinking was strengthened. She gradually overcame pain after working on those adjustment exercises. She could resume a normal way of living and is confident about her future.

Faith belongs to the spiritual aspect of holistic care. We can then do an assessment for patients based on their spirituality and give them suitable support. In America, a front line doctor proposed a simple, non-intrusive FICA question format that helps us understand the spiritual needs of patients, including:

1. Faith

Do you consider yourself spiritual?

Do you have a religious faith?

2. Importance

How important are your religious faiths and spirituality, and how might they influence decision related to your health?

3. Community

Are you part of a religious or spiritual or other community? If so, how does this community support you?

4. Address

How might I address your spiritual needs?

Chun is a Christian and she found spiritual strength through Bible studies, prayer and the help from her faith community. But we cannot ignore the physical, psychological and social assessments as these are related to one's spirituality. All these aspects are inter-related and affect the holistic health of a person. We can ask the following questions in order to understand the other aspects of patients for post-treatment assessment:

1. Physical

How has your illness affected your daily living?

2. Psychological

How do you view your sickness?

How has your illness affected your emotions?

3. Social

Has your illness affected your social role and interpersonal relationships?

## Chapter 3

### **Encouraging words from group members**

#### **1<sup>st</sup> Group - COPE programme**

(Hau Yuen) – have the motivation to live, we love ourselves before we love others

(Ying Lan) – pay attention to our appearance, be equipped with what we plan to do

(Chun Lan) – exercise daily to keep us healthy

(Shum Ngan) – do not worry, and be set free

(Sau King) – be happy, nothing is impossible

(Lai Yin) – to live is a blessing

(Chi Wai) – relax ourselves and have a peaceful heart

(Da Ka) – control pain with our thoughts

(Shum Ngan + Chi Wai) – press on and excel

(Lai Yin) – to face pain positively and embrace a fruitful life

#### **10<sup>th</sup> Group - COPE programme**

(Dai Ho) – from weakness to strength makes patients happy

(Alan) – COPE let us regain our body and heart

(Hoi Siu) – a rich girl cries for a pair of new shoes until she meets a person without feet (treasure what you have)

(Danny) – sweep your dark clouds to face a sunny tomorrow

(Joyce) – rely on yourself to face the pain and rebuild a fruitful life

(Ringo) – the road ahead is a dead end? Hope is round the corner!

(Jade) – fruitful life, Fruitful life, change our life

(Dun Ni) – fruitful life, away from anxiety, smile again and be happy forever

(Yi) – COPE changes the second half of my life

### **14<sup>th</sup> Group - COPE programme**

(Alan) – if you experience more pain, remember to relax and stretch, enhance your self-management, then you can live a new life

(Ting Ting) – look at the mirror and ask yourself how determined you are in recovering. Walk out of the comfort zone and live a fruitful life

(Mei Fong) – stay away from pain and suffering to embrace a joyful and fruitful life

(Ling) – pain is inevitable but pain and suffering is a matter of choice!

(Shing) – opportunities sweep our dust covered all over. Six weeks into the programme make us feel refreshed

(Ada) – live a life of pain without suffering together

(Yin) – COPE allows one to build up confidence and live a fruitful life

**Caption:** Group members from each intake of COPE programme shared their experience and thoughts as a form of reminder for one self and an encouragement for participants.

## **Difficulties in pain management**

Dr. Sandy Lee

### **Differences between acute and chronic pain**

Pain is inevitable, it is a part of human life. It is a form of self-protection by signaling the need to escape oneself from danger. Pain usually subsides when the original pathology is removed or controlled by treatment, and it is called “acute pain”. Such pain is short term and usually it will not be a persistent barrier to rehabilitation. However, in some patients, pain persists and becomes refractory to treatment. This form of pain, chronic pain, may not be accountable by clinical and investigation findings, or disproportionate to the results. Chronic pain differs from acute pain in the way that it doesn't has benefit to the individual. It is caused by pathological changes in the nervous system that are not reversible.

### **Classification of chronic pain**

Many clinical conditions can give rise to chronic pain, and they can be categorized according to their mechanism: nociceptive, neuropathic or mixed. Nociceptive pain arises from activation of nociceptors found in all tissues except the central nervous system. Neuropathic pain, in contrast, is caused by nerve injury or disease. Nerve damages causing by diabetes and shingles (post-herpetic neuralgia) are typical examples of neuropathic pain.

### **Impacts of chronic pain**

Unrelieved pain can be associated with severe impairment of physical, psychological conditions and social well-being. Prolonged immobility because of persistent pain, resulting in muscle wasting and joint stiffness may lead to a downward spiral of physical inactivity, decreased socialization, and sleep disruption and medications overuse. Once entrenched, these maladaptive behavior patterns are difficult to reverse. Secondary mood problems may subsequently develop, along with family dysfunction, poor work performance, unemployment, financial burden, disability, and isolation from society and family. Mood disturbances including turning inwards, frustration, bitterness, anxiety, fear, depression and suicide are not uncommon in chronic pain patients. Moreover, the economic impact of chronic pain has been shown to be significant in terms of health care utilization, social welfare expenses, litigation cost

and loss of productivity.

### **Barriers of chronic pain management**

Studies of the pathophysiologic mechanisms suggest that chronic pain is a multifactorial problem, comprising interrelated structural, functional, pathophysiological and psycho-social factors. Unrealistic expectation may aggravate the psychological barrier to grow. People often expect immediate relief from symptoms, which is difficult to achieve when it comes to chronic pain. The truth is that even the powerful medications could only be effective to a minority of patients. Besides, people are being flooded with information, and often misleading, through TV or Internet and other channels. This sort of misconceptions and in many cases, may give false hope to people about the effect from a certain drug or treatment modality.

### **Treatment approach**

The longer a pain problem persists without resolution or relief, the more intractable it becomes. Therefore early assessment and management particularly for high-risk patients are highly recommended, so as to avoid progression into chronicity and unnecessary handicap. Treatment of complex chronic pain cases can be challenging and usually requires multidisciplinary approach rather than medical treatment alone. When it is not possible to eliminate pain, emphasis of management programme should be shifted from pain relief towards maximizing patient's ability to function with pain.

### **Pain management programme**

A pain management programme based on cognitive behavioral therapy (CBT) has been shown to be helpful for improving physical function, psychological well-being, and productivity of the affected Chinese population. Successful pain management programme could provide pain education, training in communication skills and coping strategies, graded physical exercises, functional activities training and sleep hygiene. Coping skills training includes strategies on cognitive re-conceptualisation of pain, goal and action planning, activity pacing, thought challenging exercises, desensitisation and relaxation techniques etc.

Other important components of chronic pain management programme include:

#### *Self-management*

Patients who believe that they can help control or manage their pain are often referred to as having an internal locus of control. Treatment efforts should be aimed to reinforce patients' belief in their ability to affect the pain levels. Apart from this, it should also empower patients to take the responsibility of managing different aspects of life in the presence of pain, in order to improve their daily functions, mood, sleep pattern and quality of life.

#### *Relapse prevention*

As the nature of pain is chronic, it is expected that pain will persist and also fluctuates. As a result, patients are in a risk of relapse and developing into disability. This may be tackled by a certain of strategies, ideally in collaboration with patient's carers or significant others. It aims at maintaining the self-management approach by the patient with assistance in rehabilitation planning.

#### **How a programme will be successful?**

Patient selection is one of major challenges in chronic pain programme. Most of the chronic pain patients have relied on passive management of their pain for many years. Many of them are still seeking for a cure, trying out different treatment options, including traditional Chinese medicine. They may fail to accept their chronicity of pain condition. As a result, they are lack of motivation to change. So, when preparing a patient for CBT intervention, it starts with pain acceptance by reformulation of the pain experience of the patient. This is intended to help patients aware of what the pain-related problems are and what might be needed to change in order to reduce the impact on them. It encourages he/she to live with ongoing pain without attempts to avoid, reduce, or otherwise control it, and thus focus on engaging in valued activities and pursuing meaningful goals to the individual in the presence of pain. Ultimately, it may help patient to understand the management more in depth and be more compliant to the programme.

In addition, Chinese population is slow to settle into a group therapy setting. They are usually unwilling to share their problems, possibly related to cultural belief in not losing 'face' (pride) in the presence of others, and resulting in reluctance to contribute in the programme discussion and dynamics. Therefore, successful programme should be adjusted and conducted according to the population's education level, cultural background, belief and languages, when applying cognitive behavioral therapy principles, by using appropriate examples that are meaningful to the patients.

Pain is multidimensional and therefore multimodality treatment is essential to emphasize on different aspects that affecting the patient. On the other hand, inadequate communication between disciplines and diverse knowledge of treatment options may sometimes lead to confusion or frustration to patients. Therefore, a consistent approach under an interdisciplinary team is key feature of successful programme. This model is characterized by team members working together for a common goal, making collective therapeutic decisions, and having face-to-face meetings and patient team conferences to facilitate communication and consultation. Interdisciplinary teams may be led by a physician, psychologist or pain nurse. However, the access to these interdisciplinary pain programmes is not always feasible due to limited availability and restricted local resources. Nevertheless, seamless collaboration of specialists from different fields is the key to success in organizing chronic pain programme.

NICHE

## **The Historical Development of Comprehensive Outpatient Engagement Programme (COPE)**

Ms Marlene Ma

### **Background**

Chronic pain is a complicated and difficult condition. The patients' degree of pain may not be related to their illness, but is a function of their psychological, physical, emotional and social factors. Thus it is difficult to have a right diagnosis of chronic pain. Some patients still suffer much from chronic pain, and have their lives turned upside down despite undergoing various western and traditional Chinese medical treatments. When their health deteriorates, they become more depressed and cannot even involve in some basic life activities. Even when the pain subsides, their failing vitality cannot be reversed and recovered, creating various issues including medical, social and economic issues. Our medical team sometimes are at their wits' end, and we hope that there is a more effective treatment method to help these patients.

Hong Kong has been inspired by developed countries as early as in the nineties by introducing a multidisciplinary approach to chronic pain management.<sup>1</sup> But during that time only a multidisciplinary outpatient service was set up with certain specialities (including neuro surgery and orthopaedics department), and some patients were managed separately by the referral system. In 2002, the New Territories East Cluster Pain Management Centre was established at Alice Ho Miu Ling Nethersole Hospital. Our departmental head Dr Chen suggested affiliating with other key departments such as clinical psychology department, physiotherapy department, occupational therapy department, medical social work and chaplaincy department in order to provide holistic and integrated treatment, which is now known as the Comprehensive Outpatient Engagement (COPE) Program, an integrated pain self-management programme that is based on cognitive behavioural treatment. It is hoped that patients can get to grasp an effective method and techniques in alleviating pain in order to enhance their quality of life. The governing committee of Alice Ho Miu Ling Nethersole Hospital has generously supported our travels to attend the Active Day Patient Treatment (ADAPT) programme at the Royal North Shore Hospital in Australia as a way of equipping the medical team responsible for the programme.

The first batch of team members include clinical psychologist Wong Chi Ming, physiotherapist Cheung Chin Ting, occupational therapist Tse Yee Wai, chaplain Poon Yung Ho, Pain department Dr Chen and myself. We were full of excitement in this journey and never missed any breakfast or lunch meetings in order to fully grasp the essence of the ADAPT programme. This journey was very fruitful, thank the friendly and selfless mentoring of the medical team of ADAPT programme. What is eye-opening is the positive transformation of the participants at ADAPT programme. These real life examples are a boost to our team, which provide further evidence of the credibility of this treatment and the feasibility of living with pain.

### **Introduction of the programme**

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<sup>1</sup> Chen, P. P. (1996). Multidisciplinary approach to chronic pain management. *Hong Kong Medical Journal*, 2, 401-404.

Our medical team has revised the content and duration of the COPE programme for a number of times owing to the cultural differences between Hong Kong and Australia. The current programme is a 14-full day programme, which is completed within six weeks. The course will increase in depth over the period, focusing on how to change the patients' evaluation and attitude towards the experience of pain through a cognitive behavioural treatment. Patients will have an understanding of the effects of pain, and can analyse the present issues in order to establish a learning approach that can change their mind and body and that can help them learn some adjustment techniques. During the process, patients can adjust behaviours that do not yield effects and can actively re-engage themselves in a role they expect to be in.

Firstly, course facilitators will teach participants various ways and techniques in dealing with negative emotions and thoughts, as well as difficult issues in life, interpersonal problems etc. Secondly, the participants will gradually train up their physique. With the use of relaxation techniques they also try to deal with pain, insomnia, fatigue, sickness etc. Thirdly, facilitators will provide sleep analysis and tips on improving sleep. Fourthly, facilitators will provide participants with knowledge on chronic pain, including its physiology, medicine and treatment methods etc. Fifthly, participants will adjust their lifestyle, through the use of energy/effort saving tools, better postures, pacing skills, adjustment to activity level etc. The aim is to allow participants to find a way of living that enable them to live with pain. Last but not least, we will teach participants the effective use of painkillers so that they will be less reliant on such pills.

Participants of this course must first be evaluated by facilitators and must set clear and realistic targets before they enrol to the course. They must set a clear approach for their drills and practice so as to reinforce the drive for change. Participants must apply the knowledge and techniques acquired in the course in order to implement their pre-set targets. In principle, all techniques must be applied in real life in order for them to be effective.

The mentor will have three follow-up meetings with the group upon course completion. I am pleased to see that most participants can stop revisiting the pain division after the last review, because they already learn to live with pain. Through the course, participants can generally reactivate themselves, transform their thinking and better their way of living, as well as learn how to manage their pain effectively instead of resorting to clinical visitations in a reactive manner. The course successfully raises them up as strong and active self-managers.

We have published these experiences, evaluation reports and cost-benefit analysis in numerous medical journals and at international conferences in order to promote its effectiveness. It is hoped that such affirmative results can serve as a booster in the medical systems of Hong Kong and even Asia, and raise public awareness towards these chronic pain patients.

## Chapter 6

### **Sharing by the medical team in charge of Comprehensive Outpatient Engagement Programme (COPE)**

Dr Andrew Luk

COPE is a six-week intensive programme run by the pain management centre. In this programme, our multidisciplinary team will provide intensive training to help patients with self-management. The course uses cognitive behavioural therapy as its main framework. Through group meetings, and the intervention of various professions and support, the patients' perception of pain will be changed. They will get to grasp with self-management techniques, enhance their ability to cope with adversity, learn to live with pain and live a better life. From the case studies of different participants, we can see the enormous changes in their lives. Many participants can rediscover meanings of life. As a course instructor and a member of the multidisciplinary team, what are their reflections? What difficulties do they need to overcome? In the midst of limited resources, how can they maintain their enthusiasm for work?

Through a focus group sharing, I invited team members to present and share their experiences. Participants included: Dr Lee, nurse Ms Ma, occupational therapist Mr Tse, psychologist Mr Wong, chaplain Ms Hui, physiotherapist Mr Cheung, social worker Ms Cheng and Ms Wan.

(caption) interview by focus group

#### **Division of labour according to their expertise**

Dr Lee is responsible for providing accurate medical information and adjusting medication. Dr Lee said: "Patients may think that I am responsible for concrete matters such as knowledge, hardware guidelines etc; but compared with other specialties, we use a lot of time listening to patients, explaining the disease and treatment process so that they feel being cared for. This can enhance their compliance with the treatment."

Ms Ma, the nurse, is responsible for providing one-stop support and coordination. She said: "I am responsible for introducing the course, setting course dates, arranging venues and tools, liaising with team members and patients, as well as the follow up work of the course. One of the most important roles is to evaluate and select suitable patients to attend the course. I will manage participants' expectations towards the course before it starts, and I will help them deal with some thorny issues that may affect them, so that they can fully be engaged in the course. During the time of course, I will help them with tackling assignments, and reinforce the knowledge and techniques learned in the course." Besides, coordinating members with the medical team is also one of the key jobs of Ms. Ma.

Occupational therapist Mr Tse said "My main role is to enhance the patients' ability to work, self-care and entertain themselves. In a lesson on "application", I teach them how to adjust and save

energy and how to adjust human body's functions so that they can finish their chores and manage themselves strategically and at ease. In addition, I will help participants to return to their hobbies, or cultivate a habit of having leisure activities. As for rehabilitation, I will teach them setting short term and long term goals, and will refer them to join "patients' vocational training scheme" to help them rebuild a way of living."

The main role of Mr Wong, the psychologist is to evaluate. He said: "My role is mainly to provide evaluation to the participants. First of all, I will evaluate whether patients are suitable in attending the course. Secondly, I will evaluate whether they can overcome psychological barriers and fear caused by pain by understanding their views on pain. In addition, I will evaluate the patients' ways of problem solving and their adaptability. During the course period, I will evaluate their emotional stability". Mr Wong then shared the challenges he faced: "Some participants may face a lot of struggles during the course. They might say: Too many assignments, what a suffering! Some participants complain in the beginning and show resistance, but when their mind set change, they will become appreciative of us. "Mr Wong pointed out that the team will send a consistent message to the participants and will support each other. This proves to be helpful to them.

Ms Hui, the chaplain, is responsible for providing spiritual support to participants. She said: "I helped participants clarify their will in life, and help them understand how faith can support us in facing life's struggles and trauma. I will explore with participants together and reflect on their self-esteem, meaning of life, topics on love and sense of belonging, forgive and being forgiven, future hope etc. Regardless of their faith, I will explore with them: how do they understand their pain and suffering? Will they feel sad? Will they feel angry?" In addition, Ms Hui will actively cooperate with the team in observing the participants' issues as shown in the course, and will encourage them to seek advice. Ms Hui said: "The profession of chaplain can help lift their spiritual quality, inspire their deep sense of awakening, and help them achieve the ultimate purpose in life."

Physiotherapist Mr Cheung said:" The first part of my job is to carry out diagnosis together with doctors, nurses and psychologists and select suitable patients to join the programme. The second part of my job requires me to take the initiative to enhance participants' physique through movements." Mr Cheung pointed out that many patients who have been suffering from chronic pain for years have developed a fear towards pain. The prolonged lack of activity reduced their physique significantly. He will help participants improve physique. Mr Cheung said: "Participants will feel a bit stretched in the first few weeks, their pain may also increase. But pain does not mean "hurt" in Chinese. I will work with the whole team to help change their mind set. Participants may only want to reduce pain in the past but now the focus is on how to improve their physique. " In the last part of the course, Mr Cheung will serve as a coach to help participants empower themselves to enhance their physical conditions rather than simply relying on medication.

Medical social workers Ms Cheng and Ms Wan said that their roles are likened to a learning centre tutor. They said: "We are like a tutor or listener, helping participants reach their recovery targets step by step. Since the course is conducted in cell group format, we encourage the sharing and

interaction among group members as this would consolidate their sense of security and bonding and enhance group dynamics. We will also assist them in keeping contact with each other through setting up an alumni club upon graduation so that they can support each other in doing volunteering work to help others.”

### **Mutual consensus and support complementary to each other**

A successful course requires the concerted efforts of the team in overcoming challenges. The nurse, for example, needs to coordinate and liaise with patients and instructors, arrange venues, even to change the classroom to a bathroom or kitchen. Occupational therapist needs to thoroughly understand the background of patients within a very short time. They need to convert the classroom to bathroom or kitchen as a way of facilitating teaching and conducting further practices. Psychologists have to accurately evaluate the attitude of patients so that their mentality will be challenged. The chaplain needs to have a better understanding of various professions in order to support better and make arrangements. Social workers are less familiar with medication and they need to refer these questions to the medical team for follow up. Physiotherapists need to constantly evaluate the progress of participants in order to know their pace and room for improvement.

Many team members are working really hard in the process of treatment and have to work over time. In addition, in order to achieve consensus in the treatment, we have to learn to cooperate better.

### **Their life transformation becomes our driving force**

Patients’ feedback are the biggest driving force in maintaining the team’s passion. Patients’ lives are often transformed upon completion of course. Their pain is still there, but they can have a different life. These fruitful results are a big driving force to the whole team.

“The positive feedback of patients, and seeing their changes become our driving force. When we conduct initial assessment, many patients are downcast and look worried. But about a year of half after their graduation, I sometimes cannot recognize them. They are like two different people and look radiant and confident. I feel they have made great strides overall.”

“I inspired them to develop a positive attitude, mind set and values towards life, which can be used for life. I noticed that they can accept their pain without complaint. They have developed their sense of control without relying on other doctors and medication. They have gained control of their lives and can live with pain.”

“Our whole team was thrilled to meet them again. It is a form of positive reinforcement. We all feel that what we are doing is meaningful and we hope to continue to help more patients.”

### **Recognition from patients and encouragement from team members**

In addition, the appreciation of patients has been the driving force behind the team. One team member has saved up a lot of small gifts from course participants. “When I received these small gifts, I would save them up. When they come and make a re-visitation, they might sometimes pass by our unit and pay me a visit. These little things made me feel heart-warming.”

### **Recognize treatment target and focus on long term results**

Some patients require a longer recovery period, so the results of this programme may not be immediately realized. Some team members will focus more on the long term results.

“I believe that the techniques they learned regarding daily living can still be applicable five or ten years later. I will say to myself: the seeds sown today will grow as trees eight or ten years later. Many results are not immediately visible.”

### **Mutual support and trust within the healthcare team**

Other than gaining recognition from patients, other team members opined that the mutual trust and support from within the team are just as important.

“The mutual encouragement and trust among team members enhanced the cohesiveness of the whole team. In addition, the lecture materials delivered by each team member will be applied universally by all team members. This maintained the consistency of the team. We learn to complement each other and are aligned in our speech so that participants will not get confusing messages. This will also enhance the credibility of the knowledge given. There is no leading role in the whole team. Each team member has his/her unique professional role and function, and together they are happy to complement each other.”

### **Committed involvement and risen morale**

The commitment of team members is also a key in encouraging team members. At the same time, their appreciation for others can raise the morale of the team.

“In the team there are a lot of committed team members who put in a lot of efforts in coordinating the course, whether it is selection of patients, adjustment of schedule or venue arrangement, which show their patience. We all know that we should not take things for granted. Participants are able to come to the course persistently are due to the fact that some team members are as caring as caretakers. They would call up participants to continue with the course. So some team members stay up late and shed lots of tears in order to care for them. They are worthy of our appreciation.”

To conclude, the transformation of patients and their appreciation for the healthcare team provided ardent support for the team members, who become more confident in their working philosophy and meaning. Secondly, the division of labour among team members who developed rapport, mutual trust and support have been able to initiate their passion for work. Let’s hope that this programme can continue to help and bless more chronic pain patients.

## **From spiritual care to fruitful life**

Ms Janet Hui

The work and meaning of a hospital chaplain are always misunderstood as sharing the doctrine or leading people to kind deeds. In fact, our main work is to support a patient spiritually. Most people ignored the need for our intrinsic self, i.e. the spiritual needs within our body. This shows that people need to know what a healthy way of life is. A healthy life requires an appropriate development and growth of four aspects: body, mind, social and spiritual. Based on the basic needs of human being, we will strive to fulfill our physical, psychological and social needs, but spiritual needs are often being neglected. We should understand that spiritual matters can deeply affect a person's life. As a Christian chaplain, I now try to share with you the spiritual perception of Christian faith and its relevance with spiritual care, so that readers can understand our role and work in the pain treatment team.

### **What is spiritual care**

First of all, we need to understand what spiritual care means. Clinical psychologist David G Benner pointed out in his book "*Care of Souls: Revisioning Christian Nurture and Counsel*" that the soul is the intersection of the psychological and spiritual aspects. It is also the driving force behind us. When the psychological health of a patient being adversely affected by chronic pain, they need to be healed and recovered to regain their health and balance. Spiritual matters not only relate to the potential nature of one's personality and intrinsic values, but also relate to one's self-awareness, identity and reflective ability. Spirituality and religiousness are often mentioned together. Though their concepts are not easy to clarify, most people believe that the two concepts differ in the sense that religiousness are related to institution, doctrine, rituals and visible behaviours, while spirituality is related to the transcendental relationship among oneself, others and the world. The ultimate value in life and the seeking of meaning intersect with the inner, transcendental power or God. Those who values spiritual needs or believe in spiritual living may not have a specific faith, but those with faith normally values spiritual living. In the Bible, Genesis 2:7 says: "the Lord God formed the man from the dust of the ground and breathed into his nostrils the breath of life, and the man became a living being." Therefore, each and every one of us has a spiritual side, but to distinguish between a person's spirituality and religiousness is not easy.

### **Christian spiritual care**

The spiritual care in Christianity includes four main elements: healing, support, repair and guidance. Healing refers to helping with the physical and spiritual weakness of a person to attain holistic healing and holiness. Support refers to acts of care that help people overcome difficulties. Repair refers to the rebuilding of damaged relationship, including the relationship with others, with oneself and with God (or heaven for those atheists). Guidance refers to helping people make wise

decisions to attain mature spirituality. Spirituality is a gift from God. He gives people a specific task, which is to seek the deeper meaning of one's life and role. As such, spiritual care is about caring for the messages sent from the bottom of people's hearts from the spiritual and psychological perspective. Through acts of care and healing, one's perfect status that was once lost would be reinforced and repaired.

### **Spirituality and holistic health**

With the emergence of postmodern and multicultural thinking, spiritual and religious issues are growing in importance in disciplines such as medicine, psychology and sociology. In articles relating to psychiatric, psychology, religion and spirituality, they all mention the huge influence of religion and spirituality on contemporary culture, spanning clinical, consultative, physiological, psychological and interpersonal disciplines. One's health is the result of the interaction of the following six aspects: physical, emotional, social, intellectual, spiritual and occupational. Among them spiritual is considered as the deepest and most central part among all health aspects, as it can support and influence other aspects. In the past ten years there have been more and more psychologists expressing their interest in the integration of faith, spirituality and psychological treatment.

Nowadays as people strive for a living, their lives are under stress. The never ending pursuit for excellence and success, an over-emphasis of things and people they see as important, plus a blind way of living without caring for one's inner needs easily lead to an imbalanced life. It is only when a person feels his/her limit, experience frustration and helplessness will he/she stop to face one's real self. A person must return to the story of creation and establish an intimate relationship with God in order to understand one's own purpose and meaning of existence. Based on this concept, the chaplain support the patient's emotions and help them face the frustration and suffering brought about by the pain, through visitations, consolations and care. The chaplain can then respond to the patients' spiritual needs. In addition, the chaplain will share the Christian faith with patients so that they understand the relationship between Christian faith and spirituality. The chaplain also believes that a person can experience God's promise in times of crisis, for the Bible says, "But he said to me, My grace is sufficient for you, for my power is made perfect in weakness." (2 Corinthians 12:9)

God always bless them and help them come through crisis by these visitations, consolations, care and face-to-face meeting. But such acts of love by God and the acts of care by chaplain are often misunderstood as inevitably linked with religion and rituals. Some people can have their physical and psychological problems improved through the power of faith, but improvement needs not be always linked to religion. Psychological therapy can also play a part. In sum, people have their spiritual needs regardless of their participation in religious activities and rituals.

### **The role of chaplain in the treatment team**

When pain patients suffer from chronic pain, not only their body needs to be healed, their spirituality also needs to be taken care of. Uncured pain will inevitably cause frustration to the patients' psychological and physical conditions. Their road to recovery is never easy. In addition, utilitarian in the society often make patients doubt their life, their way of living and their value of existence, thereby developing a sense of frustration and depression. They will ask: "What is the value and meaning of pain to me?" In order to explore the non-conscious meaning of the issues, we need someone who can listen to them so that their deepest desire, needs and struggles can be met. The chaplain plays such a role through reestablishing a patient's spiritual health, which is the main focus and sphere of influence of a chaplain.

### **The mission of chaplain in the treatment team**

When we face the spiritual needs of patients, the role of chaplain is to diagnose and evaluate the patients' spiritual conditions, their needs and desire. They will try to find out the symptom of spiritual problem behind their pain, and to carry out an accurate diagnosis of their spiritual needs. Most importantly, we clarify the impact of their beliefs and faith on their sickness. Such impacts include self-value, meaning of existence, love and belonging, forgive and being forgiven, future hope, etc. The aim is to help patients raise their awareness towards their spiritual needs. Through caring for and listening to their needs, their problems at the spiritual level will be alleviated. Through pastoral counselling, their chances of suffering from serious spiritual problems can be reduced. When patients are being respected, accepted and understood, they can face pain much better, their life and quality in living will also be improved.

### **Taking the responsibility of holistic care**

The COPE programme is based on the philosophy of holistic treatment. Not only does it transfer knowledge, it also helps patients enhance their self-management ability, and cares for the patients' physical, psychological, social and spiritual needs. Proverbs 18:14 says: "A man's spirit sustains him in sickness, but a crushed spirit who can bear?" Spiritual weakness is more difficult to deal with than physical weakness. When a body is cured, it doesn't mean his spirit is healed. But when a spirit is healed, there comes the drive for physical healing. Philosopher Arthur Schopenhauer once commented that "The greatest of follies is to sacrifice health for any other kind of happiness." Chaplains care for the spiritual needs of patients through listening to their sharing in class and evaluate their obstacles at the spiritual level in managing pain. In addition, chaplains can show their care for pain patients and give them a helping hand. In this way, the medical service becomes more human. The chaplain believes that curing spiritual pain is not dependent on technology, but lies in such acts of concern shown towards patients, so that they can feel the love of God while in pain. Therefore, it is the important role as a chaplain to care for the patients' spiritual needs. Our team is willing to walk with them on their road to recovery so that we can be their angels in their life.

### **Holistic health and fruitful life**

Dr Andrew Luk

Everyone hopes to possess wealth, the more the better. We want to write a big sum on the cheque, whether it is one million or ten million. But when the amount on the cheque starts with zero, then our hope is shattered. Health is like the first figure in this amount, the bigger the figure, the better, the more health we gain. With health comes wealth, along with the joy that comes with wealth. When health is failing, it cannot be regained with wealth, and ultimately the joy in our life will be lost too. As such, health is the biggest wealth in our life, and we must cherish it.

What is health? According to the definition of health laid down by World Health Organization in 1946, a healthy person is not only free of any disease, but also lives in an optimal condition at the physical, psychological and social aspects. Spiritual aspect is added to the definition in 1998. Towards the end of the 20<sup>th</sup> century, holistic health becomes a hot topic in the US. In Hong Kong, healthcare organisations have also affirmed the importance of holistic health and have strived to provide care to attain holistic health at the psychological, physiological, social and spiritual aspects. For healthy adults, healthcare specialists pointed out that they should maintain a certain level of activity in order to take care of themselves. Psychologically, they should understand themselves, accept themselves, be able to manage their emotions and have rational thinking, be able to cope with changes in everyday life, big or small. Socially, they should know their role in society, build up and maintain interpersonal relationship. Spiritually, they should give full play to their potential and seek for meaning of life.

I surveyed over fifty healthcare staff in 2005 at Nethersole Hospital to explore their views on a healthy spirit. Respondents gave various feedback on what makes healthy spirit, which can be categorized into physical, psychological, social and spiritual dimensions. Research shows that a healthy spirit can bring positive impact on the individual at the physical, psychological and social level. We have different interpretations on what a healthy spirit is, but it is not a fragmented concept but an interweaved concept that affects a person at different levels. A lot of overseas research shows that a person is one integrated whole, i.e. the spiritual dimension will affect the physical dimension, the emotion, thoughts and interpersonal relationships. However, the spiritual dimension will also be affected by the physical, the emotion, thoughts and interpersonal relationships.

When our body is sick, other parts will be affected. We learn from the different experiences of chronic pain patients that our bodily pain not only affects movements and sleep quality, but also gives rise to psychological problems such as loss of control, negative thoughts etc. Socially, their interpersonal relationship will tense up due to a loss of work and a subsequent loss of their function and role in a society. Their lives will be seriously affected, and even feel a loss of meaning in life. Research has long pointed out that chronic pain can lead to loss of control of patients in many

aspects, their lives may also be in serious trouble. Fortunately, they chose to join the COPE programme and are able to walk out of the vicious cycle of chronic pain and restore a healthy way of living through self-help and the help of others. In the end, they can enjoy a fruitful life as a result.

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## Conclusion

Dr Andrew Luk

Pain is a gift given by God as a protective mechanism. We can be alerted when our body is met with internal or external danger so that we can flee. But chronic pain can have disastrous impact, even making us lose the meaning of life. From the stories of fourteen chronic pain patients we can find out the five key factors in helping one overcome pain:

### **Factor 1: training of COPE**

Many course participants shared in their stories that the self-management course gave them practical help. Through the assistance of interdisciplinary team, the patients overcame various difficulties to achieve success in the treatment, which mainly owe to the team's trust, advice and encouragement towards patients.

#### Instructors' trust

Ms Ma, who often contacted me, showed her concern to me most. Mr Wong also trusted me a lot. When I told them my conditions, they all trusted me and accepted me. They also explained to me what caused the pain. At a time when I lost faith in everything, when even my old colleagues who had known me for over a decade did not trust me, when my friends and doctors did not trust me, Ms Ma and Mr Wong did trust me. Their trust helped me restore confidence, and I started to have the motivation to try to change. (Story 11, Ken)

I later encountered Dr Lee of pain management centre who was so patient in explaining the pain to me and suggested steroid injection at my spinal cord in order to relieve pain, which can be further alleviated through exercises. When I saw that Dr Lee was helping me with all her heart, I did not feel hopeless anymore. I became more positive afterwards. (Story 10, Yiu Chuen)

#### Advice by Instructors

One of the biggest benefits out of the programme was the advice given by Ms Wan the social worker. At the conclusion of each lesson, she asked me one day, "Did you realize how many times you mentioned the term – in the past?" I then realized that I compared everything with something in the past, and this led to anger. So I learned to put the past identity behind and become an ordinary person. (story 1, Simon)

I agree with what Mr Tse the occupational therapist said "Pain is unavoidable, but it can be relieved through treatment or medication. Can suffering be avoided? Suffering is a way of thinking, and may be we just add to our own suffering without knowing it." (story 2, Ann)

#### Encouragement from instructors

Ms Ma encouraged us to do exercises and said, “If you are in pain, then take a rest, and shorten the standing time. Set a clear objective for yourself and set a time for standing, which can be half a minute or several minutes. You can then gradually increase the duration by one or two minutes each time. You need to persist and continue to work on it at home.” (story 3, Kitty)

At the beginning of the course, I had to use a stick to assist my walking. A nurse said, “If you think you must rely on the stick in order to walk, then you will always use the stick. This may lead to muscular dystrophy, and you have to suffer from chronic pain.” She suggested that I should not use a stick, but use more time in walking. I tried and I found that it worked! She said, “If you visit A&E doctor and asked for injection immediately upon feeling pain, you will feel pain again several hours after the injection. You can actually first adjust your emotions, let your calmness alleviate the pain rather than going to A&E immediately. (story 5, Maggie)

#### Setting goals and constant practice

Other than the dedicated help from healthcare workers, the programme helped participants a lot by requesting them to do exercises and set goals, compelling them to train up their physique to attain positive results:

COPE instructors taught me how to relax and reduce fear, and taught me how to set goals such as arranging daily activities so that I could have more motivation in my life. (Story 8, Yuk Fong)

The home assignments, given by instructors with clear objectives, became the driving force for applying these skills further. For instance, I feel reluctant just to walk on the street after the injury, though I enjoyed climbing in the past. As I am doing the course, I try to go for a hike and feel refreshed after taking in some fresh air. My sleep quality has also been improved. Most importantly, I feel much more relaxed and relieved just as what the instructor said. (story 2, Ann)

#### Resonating with each other

Participants’ sharing and mutual support benefit participants much. After the course, participants organized self-help support groups to further the support:

Course participants all suffered from pain of various kinds. But we resonated with each other once we had the chance to share our pain. Though this could not reduce our pain, at least we felt better through this mutual recognition and understanding. (story 4, Yuk Lan)

The amount of talking time in a day during the course is nearly equivalent to a whole week of my talking time at home. At the course we felt a sense of recognition, and could easily resonate with each other. But at home, others would feel annoyed by your talking, and I lost interest in talking anymore. (story 5, Maggie)

### **Factor 2: Enhancing Self-power**

Some participants have a strong character and would not give up easily when facing tough situations. Such stamina and courage became their driving force for seeking recovery. One's experience especially the experience in overcoming difficulties became an important resource of participants in facing adversity. Many participants said that the course could inspire them to rely on oneself and to relive their tough moments. When people could adjust their expectations, they can overcome negative thoughts and facilitate self-management ability to live a new life:

### Strong character

I realized that I am an ever-living bird. When I fell, I could rise again. My strong character helped me through various difficult moments. Our life would not be without any troubles. Occasional troubles could become a good testing ground for us to sharpen our wisdom and test our patience. When I worked as a wedding gown designer, I chose to work on challenging designs because I did not fear of challenges, which I consider as opportunities for breakthroughs. Therefore, I could do better and better. I felt that facing this pain is not different from facing the above challenges. I must have the courage and determination to overcome difficulties rather than let myself fall into the abyss. I must look forward and not to regret what should or should not be done in the past. (story 8, Yuk Fong)

I wonder whether this strong character is inborn or developed afterwards. I only know that I have been through many ups and downs in my life. I often encouraged myself by saying, "Nearly there! Nearly there!" I persisted with my conviction, and I kept moving on. I hoped that I will be recovered one day. When I learn that the situation is irreversible, I would change my plan and think of another way out. My strong character is my driving force. (story 12, Fei Long)

### Life experiences enhance resilience

Other than the care shown by family members, I got a lot of inspiration from friends. A friend who learned acupuncture by self-learning helped me with acupuncture treatment. He said that my case is not that bad compared to others. Recovery depends not only on medication and acupuncture, but also the right attitude. If I have a right attitude, be positive, I would gradually recover. His advice and help became a great support. (story 1, Simon)

When I think of my sister's family painful experiences and consequences, I quickly put aside the thought of death. My son once told me that the deaths of his uncle and aunt had caused great pain to his cousin. He asked me never to think about suicide, never to follow in their footsteps. Thus I put aside such thoughts. (story 8, Yuk Fong)

### Positive Thinking

This programme not only enhances my ability to cope with pain, but also inspires me to rely on oneself. I need to untie certain knots myself....Upon completing the programme, I try to untie these knots and try to accept the fact that I could not be as good as before. I began to accept the

fact that I cannot sit too long and need to stand up and move for a while to prevent the pain from escalating. I have to slow down my pace and understand that our body will affect our emotions. (Story 2, Ann)

COPE programme helped me learn to stop: stop complaining, stop looking for a way out, and accept that my pain is not curable, we have to learn to live with pain. In the process, I learned to move on and have an open heart. I learn to set a goal to move forward. I remember what my instructors said, “You can still eat even when one tooth falls away. When your feet are in pain, you still have your eyes, hands and brain to work for you and be a useful person.” I prepared myself psychologically that if I have to use wheelchair one day, I can still function and will not give up easily. (Story 8, Yuk Fong)

During the programme I learned to think positively, be alert to negative thoughts etc. We often are inclined to think negatively when something happened, rather than thinking of the positive side. This might become a vicious cycle. On the contrary, the happier one became, we would be less stubborn and would let go of certain things. We would then see the world as a much better place. (story 14, Chun)

### **Factor 3: importance of community support**

Nearly every participant mentioned their family and friends. In sickness or during the recovery period, the support of family and friends is very important. Though they may not fully understand patients’ feelings, and sometimes may be skeptical towards their pain, or they may not know how to take care of them, but their unwavering support for the patients became their motivation to press on:

#### Family support is never ending

Fortunately, even when others were nonchalant about my pain, my wife still trusted me and said, “Even when he lied to me, I am willing (to be cheated).” My wife did give me a great support. (story 10, Yiu Chuen)

My emotions became unstable and I would suddenly weep and suddenly lost temper. My family members became an outlet for my frustrations.... I thought about committing suicide twice or thrice in order to escape the pain and suffering. But I dropped the idea because of my love for my husband and children. When I calmed down, I realized that I am unreasonable which made my family suffer and made me feel guilty. My family has to suffer for my pain, but they accepted me and loved me. (story 13, Josephine)

#### True friends help in difficult times

My good friend came to my rescue and sent me a cheque after knowing my situation. Later I asked to postpone the date of mortgage payment, and so I could breathe a sigh of relief. (Story 6, Kwok Chung)

I was shocked by my behaviour and I switched off the tap immediately. I called up my friend who was very worried about my suicidal attempt, so she came to visit me immediately and introduced a clinical psychologist to me. After the consultation, I adjusted my attitude and did not think of committing suicide ever. (Story 7, Florence)

#### **Factor 4: faith brings hope**

Some participants turn to positive thinking because of their faith which helps them alleviate their emotions. In desperation, a strong faith can bring hope to believers which can help speed up their recovery. A faith community can also provide spiritual and practical support to patients:

I am a Buddhist, and reading Buddhist books or sacred texts helped me do away with negative emotions. I sometimes felt that the heaven allowed this pain in order to help me gain some benefits in return. My faith has helped me get out of my emotional trough, at the same time helped me turn to positive thinking. For instance, my pain caused my losing of the job, but on the other hand I gained more time taking care of my mother. When pain struck, it is painful, but after the pain, I feel peaceful and joyful again. My mother used to throw tantrums before diagnosed with dementia. The sickness is a blessing for her. I believe that Buddha will protect us, and arrange the best for us even when I am at my worst. (story 7, Florence)

Christian faith became my strength at my most helpless, difficult time. I picked up the Bible which I had put aside for a long time. During the most painful moments, I read the Bible and came across this verse, "It is precious when a person learns happiness while in pain." This reminded me that we should learn to be joyful in pain, and cherish what we have in order to have true happiness. I tried to change my thoughts so as not to be controlled by the pain... Other than reading the Bible, I listen to sermon on Saturdays which touched me and inspired me each time. I also join cell group activities and shared my experience with others, who also gave me support and encouragement. (story 14, Chun)

#### **Factor 5: It is more blessed to give than to receive**

Many participants joined volunteering work upon recovery. They can serve those in need as well as turn their focus from their own self to other needy people. Through volunteering work, they can enhance their self-confidence as well. They can show empathy towards others having been through similar experiences and become a support for peers:

When I shared with my friends about my pain problem, they encouraged me to do volunteering work. I began serving as a volunteer at elderly homes. I feel I am of use when I am able to help others, there is joy as well as direction in my life... Sometimes when I encounter people who are troubled by pain or emotional problems, I would share my own experience with them to encourage them to face the issues and undergo treatment. (story 3, Kitty)

In addition, I started volunteering, which is like killing two birds with one stone. On one hand I can help others which made me happy, on the other hand I can put aside my pain when I focused on the volunteering work. Knowing that my physique was weakened, my volunteering partner would ask me to do less labour work but focus more time on coordination, which is my strength. I even brought along my elder sister, my sons and husband to join volunteering service. It is more blessed to give than to receive. I was able to enjoy my family life at the same time, what a double blessing! (story 13, Josephine)

Other than these five key factors, it is also important to be able to utilize medical and rehabilitative resources. For example, Wan Na in story 9 heard about the pain rehabilitants' sharing from the radio programme and learned about COPE, so she contacted the pain management centre for help. Ann in story 2 consulted a psychiatrist because his bodily pain affected his mental conditions. When conditions stabilized upon diagnosis, she was referred to join COPE and continue to recover. Florence in story 7 joined a self-help support group when she was suffering from rheumatoid arthritis. These group gatherings helped her develop positive thinking. She reintegrated into the society after joining COPE with the help of instructors.

In conclusion, we cannot just rely on interdisciplinary team when facing pain. Most importantly, patients should accept their limitations and have a positive attitude to give full use of their potentials, so that they can strive to make a new living. Family and friends are also important in their supporting role. Therefore, we should cherish and build mutually supportive relationships so that we can get help in crisis. Faith plays an important role during adversity as it gives people hope. That's why spiritual care plays a role in the recovery process. Chaplains who joined COPE can create synergy effect. In addition, the self-help support group can give members a chance to help each other and allow themselves to be a blessing to others. This is the main purpose of this publication. May more patients benefit from this book and be encouraged and helped, so that they can face the various challenges on their road to recovery.

## Chapter 10

### **Mutual encouragement from Departmental Heads**

I would use the following Chinese hymn lyrics as words of encouragement for patients: Pain can be likened to ambassadors. It has its mission to accomplish. It resonates with me and together we sing the song more beautifully and truthfully. I love our Lord even deeper, even deeper, even deeper.

Dr Raymond Chen  
The first Hospital Chief Executive (1997-2004)  
Alice Ho Miu Ling Nethersole Hospital

We are standing by you, shoulder to shoulder, on your road to recovery. Your persistence give us enormous strength. The sun shines after rain and storm!

Dr. Tung Sau Ying  
Ex Hospital Chief Executive  
Alice Ho Miu Ling Nethersole Hospital and Tai Po Hospital

The feeling of pain varies from person to person, but this feeling can also make patients feel embarrassed and unbearable, helpless and hopeless. This book shows the compassionate heart, the stamina and professionalism of healthcare workers, whose job is to alleviate patients' pain and help them recover to attend holistic health. What seems easy is in fact difficult. Scripture says, whatever you do to the least of your brother that you do unto me. Through faith, hope and love, zero pain can be achieved through our concerted efforts. Even if that does not happen, we can still dance with pain and live our life happily thereafter.

Ms Elsa Tsang  
Ex General Manager (Nursing) (1997-2004)  
Alice Ho Miu Ling Nethersole Hospital.

Pain is a feeling that can be affected by our emotions, and our emotions can be affected by environment, people and events. As such, both the patients and the carers should understand the rationale behind so as to understand each other and support each other. In this way, the feeling of pain can be integrated into our life. We can live our life even better.

Ms Irene Lam  
Ex General Manager (Nursing) (2006-2013)  
Alice Ho Miu Ling Nethersole Hospital & Tai Po Hospital.

A rich life starts with our heart. Though we cannot change the environment, we can learn to change our heart and mind. When our heart and mind are changed, our behaviour will change. With behavioural change comes change of habits. With change of habits come change of way of living. When our way of living changes, our lives will change.

Dr. Kwok Wai Yee, Alice (Ph.D.)  
Senior Clinical Psychologist  
Cluster Coordinator (Clinical Psychology Department)  
NTEC, Hospital Authority

The medical team not only gives patients treatment but also shows love and concern for them, so that they have the courage to face the sickness and pain.

Ms. Gigi Fung  
General Manager (Nursing)  
Alice Ho Miu Ling Nethersole Hospital & Tai Po Hospital

Pain and suffering are in an intertwined relationship. Through the Comprehensive Outpatient Engagement Program (COPE), a collaborative effort between the pain management centre colleagues and patients, the lives of patients are transformed. The programme demonstrates a concern for life, so that the patients can reaffirm their ability and live a life with pain but not suffering.

Ms Frances Louie  
Department Manager, Occupational Therapy  
Alice Ho Miu Ling Nethersole Hospital

The road to recovery is full of challenges. Let me share with you words of encouragement from a well-known writer Xing Linzi (杏林子): “Be patient and persistent, striving and fighting, from frail to strong and from weakling to courageous; from frustration to vitality. Summon our courage, wipe our tears, and press on towards the rainbow of tomorrow. “Remember, we are cheering you on. Have faith, you can live a better life.

Mr. Anthony LAU W.K.  
Department Manager (Physiotherapy)  
Alice Ho Miu Ling Nethersole Hospital

Have faith, those who are in Christ have real peace, joy and hope. Scripture says, Rejoice in the Lord always. I will say it again: Rejoice! Do not be anxious about anything, but in every situation, by prayer and petition, with thanksgiving, present your requests to God. And the peace of God, which transcends all understanding, will guard your hearts and your minds in Christ Jesus.

Rev Charles Yu  
Chaplain i/c, Chaplaincy  
Alice Ho Miu Ling Nethersole Hospital

We often need to face various challenges and changes in our life, and if we learn to let go and accept whatever comes by, and face any situation with a positive attitude, we will certainly live a fruitful life.

Mr Victor Tam  
Department Manager  
Medical Social Work Department  
Alice Ho Miu Ling Nethersole Hospital

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## Epilogue

Dr. Chen Phoon Ping

In the year 2002, I was fortunate to meet Dr Michael Nicholas in San Diego. He has been at the forefront in developing the CBT-base pain management programme both in London & Sydney. I was easily convinced that we needed to bring the programme back to Hong Kong. It seems just like yesterday when our fellow COPE stakeholders sat down at lunch to plan the introduction of the programme in Hong Kong. I was impressed by their early enthusiasm, desire and dedication to provide an alternative form of treatment that may help chronic pain sufferers when in fact our drugs, surgery and injections have failed. In early 2003, our team visited Dr Nicholas' programme at the Royal North Shore Hospital in Sydney.

During the early years, the team encountered many challenges – administration buy-in was slow and difficult, there was no additional resources for the programme, all the English teaching material and forms had to be translated to Chinese and our patients were difficult to convince that such pain management programme will help them, as they continue to search for a definitive cause for their pain and the ultimate panacea that will cure the pain. Sadly these patients fail in their quest to find the cure. Despite all these difficulties and challenges, each discipline continued to contribute their limited resources to run two programmes a year for more than ten years. The team thrived so as to be able to continue providing treatment to the patients most affected by their pain. They were committed to teach the patients to live a “normal” life despite the pain and over 150 patients have benefited over the years. To our colleagues, I salute you!

Some of these patients have kindly agreed to share their experience in this book while their facilitators explain the programme so that more people are aware of this treatment approach. I have to congratulate the patients who have succeeded in overcoming the wrath of chronic pain especially those who had shared their stories in this book. I thank the authors for coming up with this book so that others may know that there is a good chance that there will be a bright light at the end of the tunnel.

Finally, I wish to thank all our staff who had worked so hard and enthusiastically to support the programme, their Department Heads and Hospital Chief Executives for their unfailing support all these years, so that chronic pain sufferers have an alternative treatment option to help them.

## **Nethersole Institute of Continuing Holistic Health Education (NICHE)**

Nethersole Institute of Continuing Holistic Health Education (NICHE) was established in 2002 and it has been sticking to its vision. Theory is put into practice through the aspects of education, publication and research, etc. NICHE continues the Nethersole spirit of “Compassionate Care” and its culture of “Holistic Health and Holistic Care”. Experiential educational model was used to retain and consolidate the Nethersole tradition. NICHE builds up partners with medical and nursing professions, and other organisations through collaboration to arouse the awareness of people from different walks of life on holist health, so that they can enjoy a life in abundance.

### **Vision**

To bring holistic health to mankind through promoting the awareness of holistic health and practice of holistic health care

### **Mission**

To promote lifelong learning in the pursuit of holistic health for a life in abundance; and in the art and science of holistic health care in order to serve with quality

### **Service Scope**

NICHE strives to promote the philosophy and the practice of “Holistic Health, Holistic Care” in the aspects of physical, psychological-social and spiritual through training and education, cultural promotion activity, seminar and exchange Programme, research and publication.

### **Target Participants**

- Health care workers, allied health care workers, supporting staff
- Student nurse, Nethersole School of Nursing, CUHK
- Student nurse, sister hospitals
- Organisations (e.g. private hospital, school, church, volunteer)