CHRONIC CONDITIONS SELF-MANAGEMENT

A Pocket Guide for Occupational Therapists in Singapore

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An SAOT, TTSH & NUH Publication

Preface

With the rapid medical advances, many of the conditions which our clients have are becoming chronic conditions. They may include but are not limited to: cancer, rheumatoid arthritis, diabetes, mental health, cardiac and neurological conditions.

When not well-managed, complications can occur, affecting clients' participation in meaningful occupations. Occupational Therapists (OTs) are in a unique position to support our clients in self-management, empowering them to integrate self-management strategies into their daily routine, as well as to transit to a new occupational identity with a different set of performance capacities.

This guide was developed to enable OTs to support our clients in self-management; increasing their confidence and skills to self-manage. Stories of how self-management has helped people living with chronic diseases are also shared.

The Pocket Guide is available in both soft and hard copies, OTs may choose to download the Guide on their electronic devices or keep the hardcopy as a reference.

Foreword

The prevalence of chronic conditions in Singapore is increasing with our ageing population and progressively affluent lifestyle. According to the Health Promotion Board (2012), one in 4 Singaporeans aged 40 years and above have at least one chronic condition and it includes diabetes, high blood pressure, high cholesterol and stroke.

Acquiring a chronic condition affects an individual's participation in daily occupations because its symptoms can be physically, mentally and emotionally challenging. Occupational therapists are skilled in enabling participation through analyzing the demands of the activities that are meaningful to the individual and ensuring a good match between the individual, the activity and environment for meaningful occupations to occur.

Self-management empowers individuals to understand their conditions and take responsibility for their health (NIH, 2010). The client-centered approach of occupational therapy is aligned with the principles of self-management (AOTA, 2015). Our clients should be empowered to self-manage their chronic conditions while maintaining their engagements in meaningful occupations with the support of occupational therapy.

Foreword (con't)

This is the first guide for self-management of chronic conditions that is developed in Singapore by occupational therapists. It serves to guide occupational therapists in working with clients with chronic conditions. I would like to congratulate the editors for developing this useful guide for clinical practice. It has the potential to benefit occupational therapists, and more importantly, their clients.

Lim Chun Yi, PhD

President, Singapore Association of Occupational Therapists (SAOT)

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About the Editors

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Sabrina Ow Yong is a Senior Occupational Therapist at Tan Tock Seng Hospital. She has received training at established centres in Canada on self-management for people with chronic diseases. Sabrina is also one of the speakers in the Engage in Life Programme at Tan Tock Seng Hospital, which adopts a self-management approach.

Sabrina's current work involves working with people with chronic diseases to make changes so that they can live meaningfully in the community.

Sabrina is actively involved in training occupational therapists to apply self-management strategies in their daily work. She is also an ACTA certified trainer and curriculum developer.

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Ngooi Bi Xia obtained a MSc in Occupational Therapy and a graduate certificate in chronic conditions management from the Dalhousie University.

She has been working as a Senior Occupational Therapist in National University Hospital, specializing in chronic conditions such as mental health, chronic pain and cardiac conditions, as well as involved in the program design of OT services for oncology and gestational diabetes.

She was also a recipient of various post-graduate scholarships and a local research award. Bi Xia is currently the Vice-President of the Singapore Association of Occupational Therapists.

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Introduction

What is Self-management?

Self-management, refers to an individual's ability to manage:

- symptoms,
- treatment,
- daily functioning,
- emotions,
- and interpersonal relationships,
- changes inherent in living with a chronic condition.

It involves three self-management tasks, namely:

- medical management,
- role management, and
- emotional management

(Lorig & Holman, 2003)

Tips for OTs

OTs are equipped with the skills set needed to promote, in particularly, role and emotional self-management.

Role self-management can include:

- Ways to return to previously valued activities
- Integrating lifestyle changes into daily routine
- Adjusting to new self-management tasks embedded in daily occupations

Emotional self-management acknowledges the emotional impact of chronic conditions affecting their occupational identities.

Transit to Self-management

Promoting effective self-management can be complex, particularly when transiting from diagnosis to appropriate self-management (Mead, Andres, Ramos, et al., 2010).

During this shift of self-identity and transition, one has to:

- consider connections between the causes of diseases and lifestyle,
- access, interpret and integrate advice and information,
- integrate attributions and information to implement life and changes,
- make life changes and lifestyle changes, and
- find new limits and integrate changes

These are often performed against the background of their social contexts and environment. (Astin, Horrocks & Closs, 2014)

Example: Application to Heart Failure

Consider whether past lifestyle choices, such as diet, stress and physical activity are connected to the disease. If yes, one will need to integrate lifestyle changes into daily routine.

New limits

- Motor symptoms, e.g. fatigue
- Cognitive symptoms, e.g. lack of concentration
- Psychosocial issues e.g. fear, grief

New medication side effects, e.g. diuretics, and condition management, e.g. restricting fluid intake, impact the scheduling of activities and events.

Expanded Chronic Care Model

Self-management is largely viewed in a larger eco-system, such as the Expanded Chronic Care Model (Figure 1), widely implemented to prevent and manage chronic diseases.

In the model, improved health outcomes for chronic disease management are the result of productive interactions between informed, activated patients and a prepared, proactive practice team. These take place within the context of the community and health system.

While self-management tasks require the support of health professionals, there is a stronger need for individuals to implement these changes and integrate them into their respective lifestyles (Asudulv, 2013). Therefore, individual characteristics and responsibility play a major role in the quest to achieve successful self-management (Newman, Steed & Mulligan, 2004).

There are specific and universal skills needed for mastery of self-management across all conditions.

Universal skills include:

- problem solving,
- decision making,
- action planning,
- resource ultilisation,
- and forming of patient-clinician partnership

Specific skills, e.g. diuretic titration is specific to heart failure.

Figure 1. The Expanded Chronic Care Model.

Reprinted from "The expanded chronic care model: An integration of concepts and strategies from population health promotion and the chronic care mode.", by V.J. Barr, S. Robinson, B. Marin-Link, L. Underhill, A. Dotts, D. Ravendale, & S. Salivaras, 2003, *Healthcare Quarterly, 7*(1), 73-82.

Self-Management Approaches

Individual VS Group

Self-management can occur in:

- Individual clinic or therapy visit
- Groups run by healthcare professionals
- Groups run by peer leaders
- A combination of the above

NICE (2015b) guidelines state that a group education program should be offered as the preferred option, but an alternative individual program should be provided for people unable or unwilling to participate in group education.

Evidence

Current evidence on whether self-management is optimally delivered as group or individual interventions is unclear; both have their impact and benefits (Norris et al., 2002; Grillo, et al., 2013).

Potential benefits of individual interventions

- More individualised education, treatment and lifestyle changes (Newman et al., 2009)
- More privacy and confidentiality (Newman et al., 2009)

Potential benefits of group interventions

- Greater interaction and interpersonal dynamics (Mensing & Norris, 2003)
- Foster social modeling and problem solving (Tang et al., 2006)
- Higher patient satisfaction (Newman et al., 2009)
- Potentially more cost-effective (Lawal & Lawal, 2016)

Disease-specific VS Generic

The self-management group programs can be disease-specific or generic programs.

Need for specific programs include:

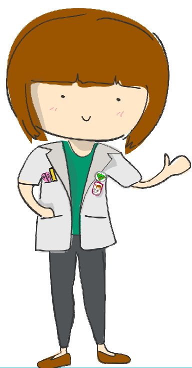
- Participants may be able to relate to each other more
- Disease-specific tasks needed for certain aspects of chronic conditions e.g. blood glucose monitoring for diabetes

Need for generic programs include:

- Co-morbidities common in ageing population
- Commonalities in the nature of self-management tasks e.g. generic approaches for psychosocial issues (Barlow et al., 2002b)
- Potential to be more cost-effective and less complicated to translate into practice (National Institutes of Health, 2000).

Evidence

Studies have shown both generic and disease-specific programs to have positive effects (Lorig et al., 2005; Ghahari et al., 2015)



Strategies to support Self-management in Clinical Practice

Behavioural Strategies

Self-management support happens when clinicians use behavioural strategies to encourage clients to actively participate towards achieving better health outcomes.

Self-management education is different from traditional education, delineated by Bodenheimer et al (2002):

Traditional education	Self-management
Widespread common problems related to specific disease	Problems identified by patient
Disease-specific; offers information and technical skills	Provides problem solving skills relevant to the consequences of chronic conditions in general
Based on theory that disease-specific knowledge creates behavioural changes, which in turn produces better outcomes	Based on theory that greater patient confidence in his/her capacity to make life-improving changes yields better clinical outcomes
Goal is compliance	Goal is increased self-efficacy and improved clinical outcomes
Health professional is the educator	Educators may be health professionals, peer leaders or other patients

Behavioural Strategies

A variety of techniques can be used, such as:

- 5As
- Building rapport
- Agenda setting e.g. agenda bubbles
- Providing information e.g. ask-tell-ask, closing the loop
- Goal setting
- Motivational interview

5As

A very useful and comprehensive approach that clinicians can use to help clients in self-management is the 5As.

The 5As

The 5As construct was developed as a strategy for smoking cessation. It is now a structure used to help clients living with chronic conditions make difficult changes in their lives (Glasgow, Goldstein, Ockene & Pronk, 2004).

1. Assess: What is the client's beliefs, behavior and knowledge?

2. Advise: Provide information that the client needs to know to consider making change.

3. Agree: Set collaborative goals with the client based on client's interest and confidence in his/her ability to change the behaviour.

4. Assist: Help the client to identify barriers to change and problem solve.

5. Arrange: Work out a follow up plan with the client, e.g. phone reviews, home or clinic visits.

Building rapport

The clinician needs to build rapport with the client, especially when making conversations about making lifestyle changes to manage the chronic condition.

The clinician needs to listen actively and address concerns of the client.

Bringing a caregiver

Bringing a caregiver or someone who could assist or support the client would also be very helpful to increase confidence to make or sustain the change.

Sometimes, the amount of information can be overwhelming for the client in one clinic/ therapy visit. The accompanying person could give confidence to the client to follow through the agreed plan for change.

Agenda setting

Clients may attend clinic/ therapy without having their questions or concerns addressed.

An initial clinic/ therapy session usually starts with the clinician interviewing and doing a thorough examination on the client.

The clinician then provides the recommended treatment or advice to the client, and facilitates the client to follow through the recommendations. There may or may not be a follow up plan.

Clients who live with chronic conditions may experience discomfort or have concerns about the disease. They need to learn to manage the condition in their everyday lives.

Clinicians need to create the opportunity for clients to voice their questions and concerns about their conditions.

Setting the visit agenda is helpful in ensuring that both the client's and clinician's concerns are addressed and prioritized based on an agreement between the client and clinician.

Try to focus on 2 or 3 visit agenda.

Agenda setting

Agenda Bubbles

The Agenda Bubbles (Figure 2) is a good tool to use in setting visit agenda. The clinician can fill in a few bubbles with the agenda that needs to be addressed and leaves the rest of the bubbles blank for the client's agenda.

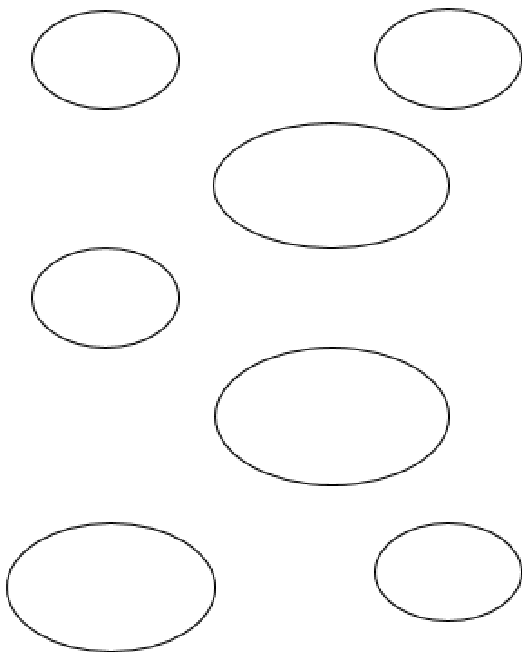


Figure 2. Agenda Bubbles

Providing information

Clients sometimes leave the clinic/ therapy session feeling overwhelmed with information or did not get the information that they want.

This may diminish their confidence in managing the chronic condition.

They may soon forget the education given and this does not help them to make positive changes for better health outcomes.

Clinicians need to communicate effectively and a useful technique they may use is Ask-Tell-Ask and Closing the Loop.

Closing the Loop
Closing the loop may be helpful in avoiding miscommunication as the clinician checks on the client's understanding of the information provided.

Ask-Tell-Ask
Ask: The clinician may start with asking the client what questions or concerns that he or she may have. The clinician may also ask the client what information he/she already knows and what further queries that he/she has.

Tell: The clinician provides the information to the client as enquired.

Ask: The clinician then asks the client to explain the information back. This is to check on his/her understanding and to close the loop. The clinician should clarify if there is any missing important information or discrepancies.

Goal Setting

Setting collaborative goals between the client and clinician is a vital step in the 5As Construct which was discussed earlier.

Goals that are SMART are easier to achieve. Refer to Figure 3 for an example of a goal setting template.

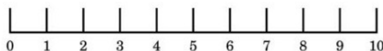
SMART goals are:

Specific
Measureable
Attainable
Relevant
Timely

When setting goals, the clinician should also discuss possible barriers to achieving the goals and support the client in problem solving to overcome these challenges.

It is helpful to check on the client's confidence level to identify these possible barriers.

Example
"On a scale of 0 to 10, how confident are you to achieve this goal?"



Follow up with:
(1) "I am curious why you chose a 6 and not a 4". This will illicit strengths and facilitators to change.

(2) "So what can bring you up 2 points, to an 8?". This will facilitate change talk and concrete action plans.

My Action Plan

Occupational Therapy

Work on an activity that is meaningful to me to prevent falls:

Stay more physically active:

____

Make my home safe:

____

Take my medication:

____

Maintain or improve my social network:

____

Have a healthy diet:

____

This is how confident I am that I will be able to carry out my action plan:

Frequency and when: ____________________

Possible difficulties: ____________________

Overcoming possible difficulties:

____

Your Name: ____________________

Your signature: ____________________ **Date:** ____________

Figure 3. Goal Setting Template

Motivational Interview

Motivational interviewing (MI) was first developed by Miller in 1980s and the it was further expanded upon with Rollnick (Miller & Rollnick, 2013).

It is used to prepare people for change, which is very often used in self-management. It is not a counseling method but a way of communication.

There are four principles in MI:

1. **Express empathy**
2. **Develop discrepancy**
3. **Support self-motivational statements**
4. **Roll with resistance**

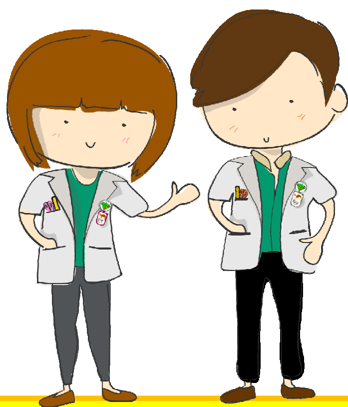
Examples of questions

Express empathy: “Many people report feeling like you do. They want to do their daily activities like they used to do, but find it difficult with less energy.”

Develop discrepancy: “You have been tripping and falling at home but yet you think your home environment is free from fall hazards, don’t you?”

Support self-motivational statements: “Based on your self-monitoring logs, you have not been drinking sugar drinks daily. In fact, you only drank once last week. How were you able to do that?” Follow-up by asking, “How do you feel about the change?”

Roll with resistance: “Maybe you should continue ___, that is ok if you do not want to quit.”



Success Stories

Success Stories

Self-management support has helped people with chronic conditions in different settings e.g. inpatient, outpatient and in the community. Occupational therapists can support people with the following chronic conditions in self-management:

- Arthritis
- Repetitive strain injuries
- Chronic pain
- Stroke
- Parkinson's Disease
- Cardiac conditions
- Chronic obstructive pulmonary disease
- Renal conditions
- Cancer
- And other chronic conditions

The editors collated case studies from Occupational Therapists (OT) who had successfully assisted people with chronic conditions in self-management. There are two patients sharing about their experiences in learning how to self-manage upon the onset of diabetes, which is the chronic condition identified to be targeted by Singapore' Ministry of Health (MOH). These stories show the roles of other healthcare professionals in supporting patients in self-management, and how patients' motivation for making and sustaining changes has been helpful. As OTs, while we read through the cases, let us think about the occupational changes and transition that they undergone and how OT can play a role in our patients' journey.

These stories are based on real life situations and patients' names have been changed for confidentiality reasons.

Case Study 1: Going Out

Background:
Ali is a 68 year old Malay Gentlemen. He was premorbidly independent in performing his activities of daily living and did not ambulate with aids. He lives in a 5-room HDB flat with his wife and daughter. His wife is a home maker.

Chronic disease:
Ali has chronic conditions which included Parkinson's Disease diagnosed since year 2004.

Impact from chronic condition:
Ali had 3 previous falls in the past one year: 2 happened outdoors and 1 within his home. All occurred when he experienced symptoms of freezing and loss of balance while walking. Ali was community ambulant until a recent fall in the past one year. After the fall, he used a 4-wheel rollator frame to walk and did not go outdoors as he was not confident.

Self-management intervention:
He was seen by a geriatrician who identified his fall etiology as Parkinson's Disease with freezing gait. He was then referred to Occupational Therapist (OT) to conduct a home assessment and make recommendations for home safety.

At the home visit, the OT used the Agenda Bubbles to set visit agenda with Ali. Besides home safety recommendations, Ali identified activity scheduling and going outdoors as agenda that he hoped to work with the Occupational Therapist.

Strategies illustrated
•Setting visit agenda using Agenda Bubbles

Case Study 1: Going Out (Con't)

The OT assessed the home environment and using the Ask-Tell-Ask and Closing the Loop technique, discussed and provided Ali and his family information about home modifications that they could consider making. The OT also checked for Ali's confidence level to make the changes suggested. Ali identified the possible barriers and indicated areas that he was not confident of. The OT then guided him in problem solving for these possible barriers. Ali and his wife agreed on a collaborative plan to make changes to their home environment. Ali and the OT agreed on the follow up plan.

At the subsequent sessions, the agenda of activity scheduling and community mobility were explored. Ali and the OT agreed on a collaborative goal and the goal was reviewed at each session. Ali identified there were changes that he would need to make in his routine.

Ali finally achieved his goals of going outdoors with his rollator frame to the park near his HDB flat, and to the supermarket with supervision from his wife. Ali was able to problem solve to manage the impact of his chronic condition and discharged from OT.

Strategies illustrated

- Ask-Tell-Ask and Closing the Loop
- Checking for confidence
- Problem solving
- Goal setting and Action Planning

Case Study 2: Heart at Work

Background:
Mr Lee is a 55 year old Chinese gentlemen. He works as a civil engineer for long hours each day. He lives in a 5-room HDB flat with his wife. His wife is a home maker.

Chronic disease:
Mr Lee has chronic conditions such as hypertension and high cholesterol. He just suffered from a heart attack and went through an operation.

Impact from chronic condition:
Mr Lee is a highly educated man with good health literacy. Although he can identify high stress, limited exercises and poor diet as contributors to his chronic conditions, he feels that he will not be able to make any changes due to his busy work schedule.

Self-management intervention:
He was seen by a cardiologist post operation and found to have poor sleep due to worries about his ability to return to work. He was then referred to the Occupational Therapist (OT) to work on sleep and lifestyle modifications.

During the initial assessment, Mr Lee appeared to be ambivalent about making any lifestyle changes. However, he was open to explore how he can return to work safely and improve his sleep. He also identified his wife as his main motivator.

Strategies illustrated
- Building rapport, problems identified by patient
- Assess readiness to change, facilitators and barriers to change

Case Study 2: Heart at work (Con't)

When discussing about plans for return to work, and techniques to assist in better sleep, the OT facilitated gradual awareness of how lifestyle changes can be inserted in an incremental manner, citing examples from other similar patients.

For the subsequent sessions, Mrs Lee was also invited to join in. Communication was facilitated between the couple and Mrs Lee expressed great concerns over the Mr Lee's health. It was then decided that Mr Lee will try to make lifestyle changes with Mrs Lee's support.

SMART goals were set (examples):
-Mr Lee will be able to go for brisk walking with Mrs Lee for at least 30mins on Sunday by 2/52
-Mr Lee will pack healthy lunches from home (prepared by Mrs Lee) at least 3x/ week by 2/52
-Mr Lee will practice deep breathing when he first reached his office and before sleep for at least 5mins by 1/12

Facilitators and barriers were discussed, with OT prompting Mr Lee to problem solve, utilise resources and make decisions re: his action plan. Regular follow-ups were given to reinforce change talk, increase self-efficacy and self-motivational statements. Mr Lee eventually achieved maintenance stage of change and was discharged from OT.

Strategies illustrated
- Self-management education; providing information
- Motivational interview
- Involvement of caregiver
- Goal setting

Case Study 3: Tired of feeling tired

Background:
Kim is a 31 year-old Chinese lady who sustained a severe traumatic brain injury (TBI) from a road traffic accident. Prior to the accident, Kim was working as an assistant human resource manager. She lives with her parents in a 4-room HDB flat. Her hobbies include reading, swimming and watching movies.

Chronic disease:
TBI results in persistent deficits in cognitive, affective and behavioural functioning that impacts one's daily activities. It is increasing recognised as is a chronic and evolving disease process.

Impact from chronic condition:
Following her injury Kim experienced some memory difficulties which she compensated well with her phone as a memory aid. She also had problems in her executive functioning (selective attention, multi-tasking, problem solving, and planning and organisation) and fatigued easily. She occasionally made socially inappropriate comments and had limited insight in managing relationship issues.

Self-management intervention:
At outpatient review, Kim verbalised her desire to return to work. Guidance was provided by the OT for Kim to identify smaller goals that she would need to achieve in order to work towards her long term goal of returning to work. One of the goals that Kim wanted to achieve was to overcome her fatigue and to complete computer assignments on time (she had problems concentrating).

Case Study 3: Tired of feeling tired (Cont'd)

The OT taught Kim to the use a fatigue diary for one week, to chart her daily activities and fatigue types (physical, mental or psychological) and levels during activities. She also rated the importance of each activity.

The OT evaluated Kim's records in the fatigue diary and taught her to look out for signs of fatigue. Based on her fatigue pattern in the day, the OT taught Kim to identify possible triggers contributing to her fatigue experience. The OT educated Kim on specific coping strategies (e.g. Rest-Activity Balance, 4Ps, "power naps", etc). Kim discussed with the OT on ways to apply these strategies in her current daily life and Kim was encouraged to think of solutions to her problems. One solution Kim identified was to review her current routine so that physically demanding activities were spread throughout the week or take short breaks in the day. An action plan was formulated together and Kim continued to monitor her fatigue level after introducing these strategies.

Case Study 3: Tired of feeling tired (Cont'd)

After the intervention, Kim reported she had improved awareness and understanding of fatigue; she also had decreased perceived impact of fatigue on daily functioning and a better sense of control over her feelings of fatigue. She managed to complete computer homework assignments consistently on time by taking a short rest period at every 30mins. She was also able to advocate for herself to make her working environment more conducive by telling her father about her needs and requesting him to lower the radio volume.

Strategies illustrated

- Education on symptoms identification and possible coping strategies
- Self-monitoring through behaviour/Fatigue charting
- Collaborative goal setting and action planning
- Collaborative problem solving

Case Study 3: Tired of feeling tired (Cont'd)

In subsequent sessions, OT continued to discuss with Kim to anticipate possible impact of fatigue and cognitive difficulties at work. Kim was guided to think of strategies to address identified issues for work scenarios. Eg. To enhance functioning during departmental meeting, some co-developed solutions may include requesting for agenda/notes prior to meeting, use of smartpen to assist with recording and reviewing meeting details, etc. Suggestions identified served as possible accommodations to be discussed with the employer. Through the guided problem solving process, Kim developed better awareness of her issues and the need to consider different options to a given problem. Being better informed, she became more confident in voicing her own needs to others.

Kim is currently back at work on a part-time basis (3 full work days per week, but flexible work hours) with some redesigning of her job scope. She reported that she is coping well and is considering talking to her supervisor about increase her work days gradually.

*** It is crucial to help individuals to better self-manage the deficits after brain injury to support their return to home and resuming of valued life roles/activities. The complexity of the consequences of brain injury necessitates a team approach to rehabilitation and developing of self-management abilities.*

Eg. In Kim's case, the psychologist also played an important role in providing psychoeducation to Kim and her family on the injury, recovery course, common neurobehavioural sequelae and possible coping strategies. Kim was also referred for social communication group co-run by speech therapist and psychologist to improve her communication skills.

Case Study 4: Calling in Pain

Background:
Ms Alimah is a 45 years old Malay lady, working as a telemarketer for 2 years. She is single, renting a room to stay near her workplace.

Chronic disease:
Ms Alimah has been suffering from pain in the neck for around 6 months. She has been using all kinds of ointments and paracetamol to relieve her pain.

Impact from chronic condition:
While the ointments and paracetamol provided temporary relief for Ms Alimah, she continued to have gradual increasing intensity of pain as the days go by. She tended to push herself to bear with the pain during work, and then would rest in bed due to pain after work. On bad days, she would also suffer from headache, leading to her taking medical leave to rest at home.

***Strategy illustrated* - 5As**

1.Assess: What is the clients' beliefs, behavior and knowledge?

•Belief: Pain is something that you just have to bear and get through it
•Behavior: Working non-stop with minimal breaks
•Knowledge: Limited knowledge about what causes the pain and what can relieve the pain. Only knows about ointments, paracetamol and rest when it is really bad.

Case Study 4: Calling in Pain (Con't)

Self-management intervention:

She was referred to the Occupational Therapist (OT) for chronic pain self-management. During initial assessment, the OT found out that in Ms Alimah's 10 hrs work, she often have to hold her phone between her shoulder and ear, and type at the same time. She only allows herself to have a half an hour lunch break, with few toilet breaks in between.

The OT also got to know that Ms Alimah was promoted 6 months ago. Ms Alimah was stressed and often had poor sleep. However, she was very motivated to make changes and was keen to learn ways to manage her pain better.

***Strategy illustrated* - 5As (Cont'd)**

2. Advise: Information to know and consider making change.
•Pain and its link to ergonomics, stress and daily activities.

3. Agree: Set collaborative goals
•Pace self at work with breaks and stretches
•Change phone to a headset
•Learn and integrate relaxation strategies into routine

4. Assist: Identify barriers to change and problem solve, e.g. too busy at work, thus forget to take breaks
•Set alarm on desktop, use a small water bottle so that she has to walk to refill more often

5. Arrange: Follow up plan with the client
•3-6 clinic sessions to learn strategies, then
•Phone call reviews to assist in maintenance stage of change
•Eventually discharged as Ms Alimah confident of managing

Patient Story 1: Solo Flight

The Beginning

I was working in South Portland, Maine (US) in 1996 as an Integrated Circuit (computer chip) design engineer. After several successful designs, I was finally tasked to design a chip on an individual basis. It was like a pilot finally authorized to fly solo. I was 28-year old then and failure on my first solo project was not an option.

My typical day ended at 2am in the morning with a drive home to clean-up and take a short sleep. I would be in the office again at 6am. Seven days a week this continued for several months. On the third month, I noticed that I beginning to urinate very frequently. No problem, I drank more Coke to replenish. I finally got worried when I noticed that I can't see clearly while driving home in the morning.

I visited the company doctor. Doctor said my blood glucose (BG) was >500mg/dl and that I am a Type 1 diabetic. He suspected that my work stress was the trigger of my problem. Information and bad news came in fast and furious. I needed to be hospitalized immediately. I need to inject insulin at least 3 times a day for the rest of my life. I need to measure my BG several times a day. I need counselling from the dietician. And if I don't manage my diabetes well, it will lead to blindness, kidney failure, nerve problem, liver failure, impotence and leg amputation. My world came crashing spectacularly down that day.

Patient Story 1: Solo Flight (Cont'd)

Critical Early Support

1. When I was in hospital, a specialised nurse educated me on how to inject insulin on myself. The dosage was prescribed by the doctor and I was to take a fixed amount of carbohydrate for each meal. The nurse also counselled on how to measure blood glucose and manage insulin attacks. I remembered that I just froze and couldn't prick my finger to take blood sample.

2. Right after several days of hospitalisation, I was put into a support group chaired by a qualified nurse where I could meet people that have similar illness. We sat in a circle and members were absolutely friendly and helpful. It was extremely comforting to be part of a group where members are out to help each other. That was critical in lighting up my world in those early days.

3. I was put into several counselling sessions with a dietician on a group basis where we can invite our spouses/partners. Many of the group members' spouses joined. In these dietician counselling sessions, it was helpful that family members were aware and shared their specific needs. I can't say enough about the importance of partner's support in those early days.

Patient Story 1: Solo Flight (Cont'd)

What Keeps Me Going

1. Look at the brighter side of things. Diabetes is a disease that I can have control to manage the illness. It's all in my own hands. I can't say that about some other diseases. I dreaded to contemplate on those deadly complications if I don't manage my diabetes. This fear kept me going. We are also very fortunate to have the internet. All the information that you want to know about diabetes are there. The more you know about the disease, the better you can manage it.

2. I would like to believe that the changes in my lifestyle in stress management, food intake and exercise have a positive impact on my physical and mental well-being.

3. My family is very precious to me. I married late and my kids are 10 and 15. I retired 2 years ago when I was 55 just so that I can spend more time with them. Once they are 18, they will have their own world. Now is a window of opportunity. They keep me going.

4. I can't thank enough of the medical and healthcare staff helping me to manage my illness. They are sincerely helpful. I am very grateful to them in helping me in my journey to manage my diabetes.

Patient Story 1: Solo Flight (Cont'd)

What Happened to the Solo Flight?

I was able to pick up all the pieces and continued to work at a more healthy pace. Yes, I managed to complete the design successfully and on schedule!

Patient Story 2: Living with Diabetes

I was the Production Director at a global MNC. I am a running fanatic, running 2 marathons a year. I am an avid traveller and nature lover, I trek once a year in third world countries within the South East Asia regions, such as in Nepal, Myanmar, Laos, Vietnam etc.

Start of my Diabetic journey:

In January 1999, I suffered a serious food poisoning after breakfast at a Malacca holiday resort and was admitted to Mount Alvernia Hospital the next morning.

I was in ICU for 4 days and spent 5 days in the recovery ward under the care of a doctor who informed me that I had an Autoimmune failure and now a Type 1 diabetes - my HbA1c is 0.

It was very frustrating in the beginning coming to terms with the diagnosis, and I was always questioning "Why me?" The first 3 months was an arduous process, learning about diabetes and how to manage the injections.

After coming to terms that I have to live with the painful injections for life, I told myself that if I want to live my normal life - travelling with my family, running, trekking and photography, I must control my diabetes and not let diabetes control me.

Patient Story 2: Living with Diabetes (Cont'd)

To learn more about diabetes control, I started to read more about it on the internet, magazines, books and attended seminars. I joined a diabetes support group in March 1999 and learned a lot through knowledge sharing with people living with Type 1 diabetes and through the doctors and nurses at the weekly support group meetings.

Getting involved in the Diabetes Support Group :

At the diabetes support group, we shared our experiences on diabetes management and created a bond amongst the members.

At the diabetes support group camp, I shared my story on how I got Type 1 diabetes. Most of the kids have Type 1 diabetes and I shared how we can still live a normal life by controlling our sugar intake and how exercise is also an important part of our blood glucose control. I brought them for morning runs and showed them how to do proper stretching exercises before and after the run.

There were kids from low income families who had high blood glucose readings. We visited their homes to share their diabetic status with their parents and we were shocked to learn from one of the parents that they do not have sufficient money for food, let alone afford the insulin for their child.

Patient Story 2: Living with Diabetes (Cont'd)

My heart dropped when I heard that and decided I had to do something about it. With the blessing from the management of the diabetes support group, I formed a committee to raise funds for the diabetic children.

We started the first walk at MacRitchie Reservoir in 1999 and managed to raise $34,000. It was a great sense of satisfaction and achievement after seeing the success of the walk. This was my second charity fund raiser, the first was the 25 km run in 1990 where we raised $32,000 with the help of my running club. The money went to the purchase of a dialysis machine and was placed at a dialysis centre.

My Motivation:

I keep a record on the food I eat and check my Pre and Post (after 2 hours) Blood Glucose (BG) daily. It takes a lot of discipline and diligence to upkeep the record. It is easier to manage the food carbohydrates and calories with home cooked food, as it is tough to estimate the food calories when dining out because we do not know how much sugar or other sweeteners were added. It is always a challenge to manage the food carbohydrate calories. I do so by updating the daily records of the food calories in my computer weekly.

Patient Story 2: Living with Diabetes (Cont'd)

I do my carbohydrate count and predict my morning BG level with a target of +/- 10 %. If I meet my morning BG target, I will be motivated and feel uplifted the whole day. If my BG target is off target, I would analyse what went wrong:

A. Did I missed my insulin jab?
B. Is it a rebound?
C. Is my night snack calories too high?
D. Did I do any heavy activities in the Day? i.e. running, walking.

I will do more BG checks to ensure it is back to normal. After every HbA1c test, I will set a target to improve the result by 0.2%, which motivates me to do my HbA1c test. I started to split my breakfast insulin shots into 2 - 630am and 1030am. It helps me to control my BG better.

With internet today, we have access to vast information and sharing experiences with fellow diabetics. I frequent the American Diabetes Association website, save relevant/important information in my computer and mobile phone and share it with my staff and friends. By sharing the information, it helps to reinforce my memory. I will educate them on hypoglycaemic symptoms, seek their understanding to not get angry when I become agitated during my hypoglycaemic state and to offer me a sugar drink instead like isotonic drinks or juices. I will also guide those who are recently diagnosed with diabetes and I feel very motivated when they show interest in managing their diabetes control.

Patient Story 2: Living with Diabetes (Cont'd)

I went for my first holiday since getting diabetes in June 1999 to New Zealand and it was an additional challenge managing diabetes in winter. Being unsure and "kiasu", I brought additional insulin and glucose meter. I realised that the blood glucose drops faster than expected in cold weather, after experiencing a few hypos. I did 2 more tests on my blood glucose, total 7- 8 times daily. I experimented by reducing 1 unit of insulin and eating more carbohydrates and I got the hang of managing the insulin dosage after a few days.

Being more confident of managing my diabetes, I went for a holiday to USA with my family in December 1999. From then on, I went on to explore the world, all the while experimenting with different climates. I went to Gobi desert in China where temperatures soared at 45 degree Celsius and Jilin, China where temperatures went as cold as -39 degree Celsius. I also went to Tibet for 26 days tracking at high altitude average 14,000 feet.

The nurse clinician recommended me to read "Calorie King", a book on the carbohydrate counter, focusing mainly on fast food. Eg: A small McDonald fries contains 230 calories of which 120 calories are carbohydrates. This book helps me to be more mindful of what I eat. Although I have already refrained from taking fast food, I do make exceptions when travelling due to time constraints.

Patient Story 2: Living with Diabetes (Cont'd)

The nurse clinician also informed me about the Energy & Nutrient Composition of Food on the Health Promotion Board website which shows the carbohydrate calories for local food. I find it very useful and relevant for me. If I am eating out, I will refer to the website and check the carbohydrate calories after deciding what to eat. I will then adjust my insulin units accordingly. I also make it a point to check the food value list when I am in the bus or train to remember the food calories and also to improve my memory. My friends were impressed when I could tell them the calories amount for wanton noodles (160 calories) and prawn noodle soup (200 calories).

Sometimes while enjoying the food, I forget to inject my insulin shots. It happens to everyone especially when you are busy or stressed. To overcome that, I set an alarm to remind me on my insulin jabs and record the Insulin units and calories in my book.

Conclusion:

Living with diabetes is a way of life. By learning how to control your diabetes, you can continue to live your life normally. I openly share information on diabetes with my friends because having a support group is important. They help look out for me and check in if I have taken my insulin jabs.

By always learning new things on how to improve my diabetes control and looking out for new technology for diabetes management, I am in control of my life.

Concluding Words

Chronic disease is a new plague affecting our society and worldwide, the incidence of chronic diseases is on the rise. In Singapore we currently have 40000 people suffering from Diabetes mellitus and in 2050 this number will increase to 1 million. Management of chronic diseases often requires some changes in behaviour as it is usually associated with physical limitations and pain. Medical treatment that is focused on treating the disease often neglects the needs of the patients which results in poorer outcomes, adherence and patient satisfaction.

Teaching patients self-management skills has shown that they have a better understanding about their illnesses and are more likely to engage in healthy behaviours.

The Chronic Care Model emphasizes the central role the patient has in their care with Self-management as one of the tools in helping them manage their chronic diseases. To empower patients to be active and motivated, we need to build health teams who are prepared and skilled in educating and supporting their patients in making behaviour changes. Self management requires a different relationship between the health care provider and the patient, with the patient at the centre of the conversation and decision making. It requires the health care personnel to be a provider of information, a coach in building confidence as well as a provider of care.

Concluding Words (Con't)

The Pocket Guide developed by the department of Occupational Therapy in TTSH, with collaboration with NUH and SAOT, is a step by step guide that outlines the essential components of self management and how to use it with their patients. I hope that it will encourage health professionals to use self management approach in the care of their patients and that it will help to empower the individual patients to be partners in the health journey.

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Acknowledgements

The editors would like to acknowledge the following people and organisations for their contribution to this Pocket Guide:

•Singapore Association of Occupational Therapists
•TTSH OT Day 2017 Sponsors
•Florence Cheong
•Heidi Tan
•Debbie Boey
•Soh Yan Ming
•Wong Su Ren
•Tan Lay Lay
•Joyce Lian Xia
•Dr Michelle Jong
•Dr Daniel Chew
•Professor Tanya Packer
•Lim Yee Jay
•Rhea Subasinghe
•Eddy Heedayat
•Jolyn Wong
•Wong Mei Xue
•Low Zheng Yi
•Tristan Mosura
•Sandy Ong Yueh Chyn
•Alodie Lim
•Lim Choo Harn
•Teri Tham
•Catherine Molod
•The two patients who shared their stories