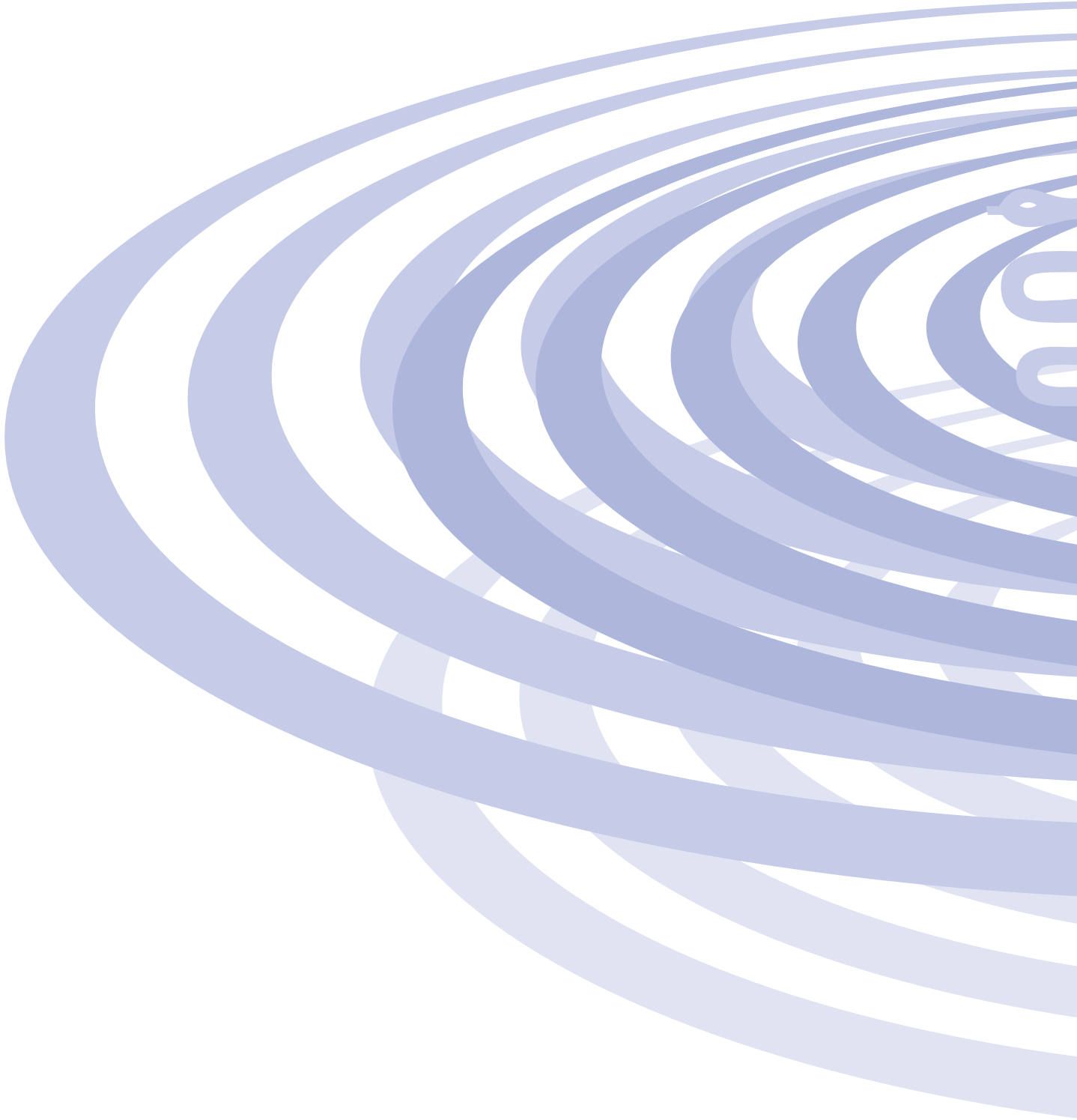


CHRONIC DISEASE SELF MANAGEMENT  
**A Guide to Implementation**

2007



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*This resource was funded by the Australian Government Department of Health and Ageing and developed by the Canning Division of General Practice.*

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## Introduction

This manual has been developed to assist health professionals (such as GPs, nurses and allied health professionals) in developing a chronic disease self management (CDSM) program within their own organisation.

The manual will provide readers with background information on chronic disease self management in Australia and describe in detail, the essential components of a successful CDSM program. This manual is based on the experiences of the Canning Division of General Practice (CDGP) CDSM program and the learnings of the Sharing Health Care Initiative. The steps involved in developing a CDSM program, types of interventions that can be offered to clients and the self management training requirements of health professionals involved in CDSM are all included in this manual.

Brief examples of the CDGP program are also threaded throughout the manual as applied examples of a CDSM model.

# 1 Chronic Disease Self Management (CDSM)

## 1.1 Background

### 1.1.1 Chronic Disease

Much of the Australian burden of disease and injury is due to chronic diseases such as type 2 diabetes and cardiovascular diseases (Haskell, 2003). Chronic conditions, or 'lifestyle' diseases, as they are often termed, presently make up more than 70% of Australia's overall disease burden due to death, disability and diminished quality of life (AIHW, 2002). Chronic diseases are very common with 77% of the population having at least one long term condition (AIHW, 2006). In the past, infectious disease was the main cause of mortality and morbidity in developed countries however this has now changed to chronic disease (WHO, 2002).

The increase in chronic disease can be attributed to a range of factors. These include:

- Advances in the prevention and treatment of infectious diseases
- Demographic changes
- Lifestyle changes
  - Tobacco smoking
  - High risk alcohol use
  - Insufficient physical activity
  - Poor diet and nutrition
  - Excess weight
  - High blood pressure
  - High blood cholesterol (AIHW, 2002).

In the past, products which have historically been marketed to Western society to better lifestyle and increase enjoyment of life have now come to the forefront as the main contributing factors towards disease and death. For example, type 2 diabetes is highly associated with obesity, lack of exercise and unhealthy eating practices. In the year 2000, the estimated number of Australians with diabetes was 940,000, however by the year 2010 it is predicted that there will be an estimated 1.23 million persons with diabetes, with the majority being type 2 diabetes (Health Insite, 2005). Other alarming statistics demonstrating the behaviours that are contributing to the rise in chronic diseases include:

- More than 85% of adults are not consuming enough vegetables;
- One in two adults are not getting sufficient physical activity;
- Almost 50% of adults are not consuming enough fruit; and
- Around 21% of adults smoke tobacco (AIHW, 2006)

In the past decade, chronic conditions have been predominantly associated with people over the age of 50, however, the number of younger people with risk factors for chronic disease is rising (Gungor, Thompson, Sutton-Tyrrell, Janosky & Arslanian, 2005). Children are becoming increasingly overweight or obese due to physical inactivity and poor diet (i.e. excess calories), leading to a multitude of problems and diseases in childhood, adolescence and adulthood. Research has shown that almost 10% of Australian children aged between 0-14 years have three or more long-term conditions (AIHW, 2006).

Chronic diseases are ongoing and incurable in nature. The expected increase in the burden of chronic disease will place great strain on health service organisations such as general practices and hospitals. Current data shows that 70% of GP visits are for patients with chronic diseases (AIHW, 2006).

Financially, chronic diseases are also a burden on the health system. In 2000-01 they accounted for nearly 70% of the total health expenditure allocated to diseases (AIHW, 2006). Without satisfactory prevention or treatment programs, the rising prevalence of these conditions will have huge implications for public health and health service expenditure in the future.

The current system of health care is still based on an ‘acute’ model. This model is highly dependent on professional care and short term services for the person with a chronic condition. There is now significant evidence stating that the successful management of a person’s (client) chronic condition is highly dependent on the self management skills of the client themselves. Health professionals and health organisations should possess the skills and capacity to facilitate self management in their clients and engage them in the management of their health condition.

### **1.1.2 CDSM – what does it mean?**

Self management is about people being actively involved in and being at the centre of their own health care to maximise their quality of life.

Self management involves the client with chronic disease:

“... engaging in activities that protect and promote health, monitoring and managing of symptoms and signs of illness, managing the impacts of illness on functioning, emotions and interpersonal relationships and adhering to treatment regimes” (Gruman & Von Korff, 1996, p.1)

Self management also involves the health care professional enabling their clients to:

“... make informed choices, to adapt new perspectives and generic skills that can be applied to new problems as they arise, to practice new health behaviours, and to maintain or regain emotional stability” (Lorig, Mazonson & Holman, 1993).

Self management requires the person, their family and carers, service providers and the health system working together to achieve better health outcomes.

### **1.1.3 Successful CDSM**

Reviews of self management programs have shown that they lead to improvements in health and other behaviours, improvements in health status (including physical functioning and psychological wellbeing) and reductions in unplanned health service utilisation (e.g. emergency departments, GPs etc) (Battersby, Ask, Reece, Markwick & Collins, 2003).

An effective self management support program should:

- Involve the facilitation of clients and families to cope with the challenges of living with and caring for chronic conditions in ways that minimise complications, symptoms and disability;
- Rely on a collaborative process between clients and health care providers to define problems, set priorities, establish goals, create treatment plans and solve problems along the way;
- Allow for self management training for both clients and health care providers;
- Incorporate active and sustained follow up (Battersby et al, 2003).

After an extensive literature search of CDSM programs, Flinders Human Behaviour and Health Research Unit (FHB&HRU) concluded that there are six main CDSM principles that underlie good self management. These principles should be used as a guide by health professionals in all stages from program development through to implementation. These principles are:

#### **1.1.3.1 Knowledge**

It is important that a person with a chronic disease has knowledge about their condition. There are different levels of knowing your condition and some of these include:

- Knowing what the condition is
- Knowing what the cause(s) of the condition are
- Knowing what happens because of the condition
- Knowing about the treatment options (including medications)
- Knowing what the side effects might be
- Knowing what may happen if the treatment stops
- Knowing what other treatment options might be available



Figure 1 depicts an example of a care plan. Ideally, a care plan should contain a list of issues (medical and non-medical) related to the client's chronic condition(s), which have been previously explored through an interview with their health professional(s). Each issue should have an aim, an intervention, person responsible and review date recorded on the form.

*For example:*

**Issue:** I do not know what all my medications are for.

**Aim:** To increase my knowledge of my medications.

**Intervention:** I will ask my GP to arrange a Home Medicine Review with a pharmacist.

**Person responsible:** GP and pharmacist

**Review Date:** 1 month

The care plan should contain all the information about the management of the condition and is an 'active' document that should be taken to all appointments and refined in view of the client's progress. The client should always have a copy of the plan as well as any other health professionals involved in the management of the client's health care.

#### 1.1.3.4 Monitoring and responding

Being able to monitor one's symptoms correctly and respond appropriately is vital in the management of chronic conditions and includes:

- Knowing what the early warning signs and symptoms are
- Measuring and recording signs and symptoms
- Knowing what to do if the symptoms get worse

For example, many disease-specific organisations and health professionals encourage the use of a symptom monitoring diary to record the daily ups and downs of having a chronic condition. This allows them to check how the client felt in between visits. In the acute care model, clients present to a health professional when they are showing signs and symptoms, so the health professional is unaware of how the client was managing in between visits. In the chronic care model, it is important that the client is encouraged to record what has happened in the management of their condition in between regular planned appointments including:

- Date
- Time
- What the symptom was
- What the measurement was
- How long the symptom lasted for
- How the client responded



A CDSM program should also be able to raise the awareness of and encourage healthy behaviours. This may mean providing education on what a healthy lifestyle is, by acting as a support through behaviour change of the client or by being a conduit to the appropriate services that can provide this information.

**WA Example**

*The Live Life Club organises many guest speakers who encourage people to live a healthy lifestyle. Nutritionists speak about healthy food options, physiotherapists talk about being more physically active and organisations that are more ‘alternative’ (such as Tai Chi Australia) promote their approach to stress management. People in the group are encouraged to give these things a go before deciding if it does or doesn’t work for them.*

**Family/carer understanding**

The support of those closest to a person with a chronic condition is crucial in the management of any illness. Lack of support from family, friends and carers can reduce confidence and hinder the management of a chronic illness. A good self manager should be able to call on family and friends for not only physical support, but also emotional and social support. A CDSM program should always make provision for family, friends and carers in any interventions.

**WA Example**

*In all interventions, family/carers were encouraged to come along with their loved ones. Significant others are able to demonstrate their support by coming along and may give their loved one additional confidence to attend the program. This will also improve understanding of their loved one’s chronic condition and how they can assist them to self manage their health.*

**1.1.4 Barriers to Successful Self Management**

A CDSM program should recognise that there are barriers which can prevent clients from self managing effectively. There are numerous factors that stand in the way of a client being able to live a healthy lifestyle with a chronic condition and it is important that these factors are taken into account when working with clients. Traditionally, chronic conditions have been treated in an ‘acute manner’ and are very ‘disease focused’. Clients are treated according to their symptoms, without the client’s life circumstances being taken into account.

Chronic diseases can occur in any socioeconomic cohort of people, however, evidence suggests that poor social and economic circumstances have a huge negative impact on health. Life expectancy is shorter and diseases are more common further down the social ladder in each society. Both material and psychosocial causes contribute to these differences and their effects extend to most diseases and causes of death (Wilkinson & Marmot, 2003).

When setting up a CDSM program, it is important that the determinants of health as listed below are taken into account. The following list is certainly not exhaustive, but gives an idea of what other issues may be present in a client’s life and is preventing them from self managing:

**Work**

- Over employment (over working)
- Underemployment (not working or not enough work)
- Unsatisfactory working conditions
- Job insecurity
- Work related stress

**Social support**

- Absence of/or unsupportive family/friends
- Social isolation
- Social exclusion

### **Housing**

- Material disadvantage
- Poor (or unsafe, insecure, unhealthy) housing

### **Transport**

- No access to car
- No access to public transport
- Inability to walk far/cycle
- No access to a driver

### **Food**

- Poor diet
- Inadequate food supply
- Inability to prepare healthy food
- Lack of knowledge about healthy/nutritious food

### **Addiction**

- Excessive alcohol
- Drug intake
- Tobacco usage

### **Stress**

- Continuing anxiety
- Insecurity
- Low self esteem
- Lack of control over work and/or home life

### **Social / Cultural Diversity**

- Language barriers
- Cultural beliefs
- Religious beliefs
- Cultural values
- Lack of access to culturally appropriate care

CDSM programs should take a holistic approach to care and take into account the medical and non medical issues that are impacting on a client's life. It is highly unlikely that a client will be managing their condition well if they are experiencing some of the barriers mentioned.

#### **Handy Hint!**

All CDSM programs need to acknowledge the 'non-medical' issues that impact on health.

The Flinders Human Behaviour and Health Research Unit has developed a suite of chronic condition self management assessment tools in their Model of Chronic Care (see Section 5.2). One tool is the Cue and Response Interview, which incorporates a series of questions, which allows the health professional to explore the client's barriers to self management.

#### **For example:**

##### *Question 5b*

#### **Attending Appointments**

- What prevents you from attending your appointments? (eg transport problems, costs, physical disability).

##### *Question 9*

#### **Managing Symptoms**

- What do you do if your signs or symptoms get worse?
- What helps you to take the recommended action?
- What stops you from taking the recommended action?
- How is your family/carer/other involved?

**WA Example**

*Members of the Live Life Club are given the responsibility of selecting what topics they want to learn more about at the meetings. Quite frequently, topics are suggested which are not 'traditional' medical topics but rather address some of the barriers to self management. Some examples have been asking local police to present information on 'safety for seniors' and having a financial advisor from Centrelink offer information on estate planning, using Centrelink services and managing money.*

**1.1.5 Chronic Disease Management in Australia**

Chronic disease management in Australia operates on many levels from public health through to hospital care. People with chronic diseases require a range of health and social services including GPs, dentists, specialist medical and dental services, counselling services, hospital services, allied health care services, pharmacy services, disability support services and aged care services. The types of services required vary according to the type and severity of the disease (AIHW, 2006).

Over the last decade many initiatives and projects have been developed to trial new ways of improving the health related quality of life for people with chronic conditions, to encourage people to use the health care system more effectively and to enhance collaboration between individuals and health care professionals. One such program was the Sharing Health Care Initiative.

**1.1.6 Sharing Health Care Initiative (SHCI)**

The Australian Government's \$36.2 million (1999-07) SHCI tested, through a series of demonstration projects, a range of CDSM models that could be suitable for use within the Australian health care system. Supporting the projects was a range of education and training materials for consumers and health providers and a national evaluation.

There were 12 SHCI demonstration projects implemented throughout Australia and each targeted different geographical, socioeconomic and disease cohorts. The objectives of the projects were to improve the health-related quality of life for people with chronic conditions, particularly those with co-morbidities; improve the use of the health care system by people with chronic conditions; and encourage collaboration between clients, their families and health service professionals in the management of chronic conditions. At the time of writing this manual there are still ongoing transitional projects, which originated during the SHCI, in operation throughout Australia.

These projects were ever-evolving and rather than randomised control trials, were more formative action-research projects that were heavily evaluated at the local and national level. The national evaluation of the SHCI demonstration projects showed:

- Improvements in the majority of indices including health status and increased symptom control
- Reduced GP visits and overnight hospital stays
- Major changes occurred within the first six to eight months and were sustained
- Consistent improvements arose in those projects involving active involvement by health professionals and GPs (from <http://www.health.gov.au/internet/wcms/publishing.nsf/Content/chronicdisease-sharing.htm>)

The SHCI targeted mature aged adults (50 years or older; or 35 years or older for Indigenous adults) with chronic and complex conditions such as:

- Diabetes
- Osteoporosis
- Arthritis
- Respiratory disorders
- Cardiovascular disease
- Depression (as co-morbidity)

### 1.1.7 Sharing Health Care Initiative – Western Australia

The SHCI Demonstration Project that was located in WA was named *Health Partners* and was run under the auspices of Canning Division of General Practice (CDGP). This project operated in the South East region of Perth for clients over the age of 50 with cardiovascular disease and/or diabetes. CDGP was one of two Divisions of General Practice who coordinated the SHCI, along with the Whitehorse Division of General Practice in NSW.

#### Canning Division of General Practice (CDGP)

CDGP was formed in 1993 and is based in the Perth suburb of Bentley, Western Australia. The aim of this Division is to enhance the health of the local community by promoting the central role of general practitioners in the planning and delivery of primary health care in the region. Using links with area health services, service providers and community groups, the Division trialled a chronic disease self management program which was named *Health Partners*. The key to this particular SHCI project was the integration of general practice with other health service organisations to aid in the promotion and facilitation of self management in the chronic disease population in this region.

#### Health Partners

*Health Partners* explored new ways to support the integration of self management principles into health service provision in WA, particularly into primary care. The program involved over 500 general practice and community referred clients with chronic conditions. The *Health Partners* project is represented diagrammatically in Figure 3.

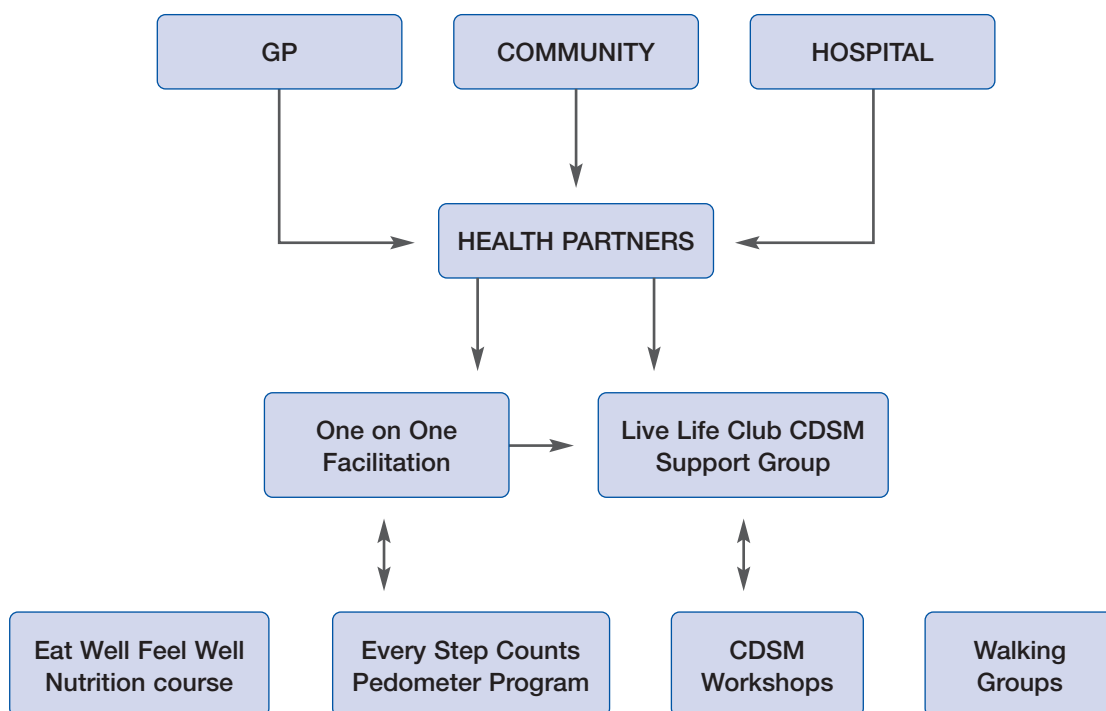


Figure 3: Health Partners CDSM Program (2001-2004)

*Health Partners* adopted a client centred approach which recognised that clients can and do play a leading role in managing their chronic condition with appropriate and timely support from service providers. *Health Partners* targeted clients in the region who were over the age of 50, with type 2 diabetes and/or cardiovascular disease with a co-existing condition. A demographic mapping of the region aided the project in targeting particular areas of high chronic disease morbidity, large ageing population and lower socioeconomic characteristics, which has been shown to be a challenging combination for the traditional medical model of health care.

The *Health Partners* project researched, developed, implemented and evaluated a suite of client interventions tailored to a specific target group in the South East metropolitan area of Perth. Over a three year period the interventions were trialled and continuously moulded based on ongoing evaluation and developments. The ever evolving nature of the program along with the significant involvement of consumers in the development and implementation of this model, has led to the present success of the program and the sustainability of many of the interventions which are still running to this day.

### **1.1.8 Building Linkages – A WA Perspective**

The delivery of CDSM can only be successful through the development of strategies that are collaborative and involve various health sectors. All sectors are able to play a crucial role in fostering chronic disease self management either directly through delivering interventions or indirectly as a funding body.

Government support can be provided through health care and funding initiatives. An example of this support is the commitment that was made to CDSM through the Commonwealth funded Sharing Health Care Initiative in 1999. This initiative was responsible for paving the way for many CDSM programs to be resourced and trialled in the community.

The support of state government is also essential for the sustainability of programs at a local level. In Western Australia, numerous CDSM profile raising strategies were initiated including meetings with WA Health representatives, presentations at conferences and general promotion within the community. This process ensured that the health sector and state government remained aware of CDSM and were kept abreast of local developments and initiatives occurring in this area.

#### ***What's happening in WA ...***

WA Health has identified six priority areas as part of its strategic intent for 2005-2010. These include:

- Healthy workforce
- Healthy hospitals
- Healthy partnerships
- Healthy communities
- Healthy resources
- Healthy leadership

Under the priority area, 'Healthy Communities', WA Health's intention is to focus on improving lifestyles, working on the prevention of ill health and the implementation of a long-term integrated health promotion program. This will be done in collaboration with government and non-government agencies, general practitioners and community groups and involve partnering with other agencies and providers. CDSM programs have the opportunity to play a significant role in addressing this priority area in Western Australia.

Building links and relationships with government and non-government agencies will be crucial in the implementation of the strategic intent for 2005-2010. Implementation will include:

- Increasing awareness of chronic disease and long-term conditions and the importance of identifying risk factors.
- Empowering communities and individuals to self manage chronic and long-term conditions.

Western Australia has the capacity and is well placed to lead the Australian community in the implementation of CDSM as a strategy to address the rising burden of chronic disease. The process of disseminating CDSM programs to the wider community will require ongoing and regular engagement with a variety of stakeholders from the health sector and funding organisations. This process of engagement and information sharing within the health sector is vital in developing a culture that supports CDSM.

## 2 Development of a CDSM Program

When developing a CDSM program it is important to have a clear outline of what the program should achieve. The best way to do this is by conducting a needs assessment to understand the specific needs and concerns of the community. The needs assessment should involve community members as well as health professionals working in the area of chronic disease. This process will help to identify the target population for the program, what interventions will be offered to address the identified needs and concerns, and the methods that will be used to evaluate the program.

### 2.1 Identify Key Stakeholders

Key stakeholders should be identified for involvement with the program. When thinking about who should be involved in this process, the following questions may aid in identifying appropriate stakeholders for the program:

- Who is responsible for the issue?
- Who might be affected by the issue (negatively or positively)?
- Who are the representatives of those likely to be affected?
- Who can make a contribution?
- Who is likely to mobilise for or against the issue?
- Who are the 'voiceless', for whom special efforts may have to be made?
- Whose absence from participation would detract from final results? (Department of Premier and Cabinet, 2002).

#### Handy Hint!

Bottom up approach!

Ensure broad and appropriate consumer and health professional involvement.

#### 2.1.1 Client Group

Some questions to consider when identifying the target population for the CDSM program include:

- What chronic condition(s) should we focus on? (eg. one or more conditions?)
- Should we focus on a particular age group?
- Are we focusing on both sexes?
- Do our clients need to be living in a particular area?
- Do we focus on a particular culture?
- Where do we recruit clients from? (eg. own organisation, GPs, self referral, other health professionals etc.) (Department of Premier and Cabinet, 2002).

#### WA Example

*The eligibility criteria for the Health Partners program were people living in the South East region of Perth, who were over the age 50 (or over 35 if ATSI) who were living with type 2 diabetes and/or cardiovascular disease.*

#### 2.1.2 General Practitioners (GPs)

For most people, GPs are the first point of contact with the health system. GPs are one crucial part of the health system for preventing and managing chronic diseases and are often the first part of the system to diagnose a chronic disease, so it is imperative that they are consulted if a CDSM program is being developed in their area. GPs manage chronic diseases by providing counselling, prescriptions for pharmaceuticals, referrals to other health services and by encouraging effective self management of chronic diseases. They also help with prevention of chronic diseases by monitoring the biomedical risk factors and giving advice on ways to modify behavioural risk factors (AIHW, 2006).

As GPs are usually the first port of call for someone with a chronic condition, it is crucial that they are involved in the development of a CDSM program within their local area. Not only will they be able to give expertise in the medical management of chronic conditions, but they will also be an excellent referral source to the program.

**Handy Hint!**

Make sure key stakeholders are involved in the development of the program.

### 2.1.3 Health and Social Service Organisations

There are many government and non-government organisations which offer community health services including public health, disease control, health promotion and research. Some also offer specific medical and equipment services for a particular condition such as asthma, diabetes, spina bifida, heart disease, multiple sclerosis or cancer. It's important to engage relevant health care providers in all aspects of the program. These health care providers are able to provide expertise in working with the target group and may also prove to be a good referral source to the program. Some other stakeholders that may be valuable to collaborate with include:

- Key health organisations, such as State Health Services, local hospitals, Asthma Foundation, Heart Foundation etc
- Local community based health organisations, such as individual HACC services
- Local social service organisations, such as Women's Health Centres and welfare organisations
- Local consumer groups
- Local network forums
- Local councils

**Handy Hint!**

Diabetes Australia and the National Heart Foundation (WA Division) were key members of the *Health Partners* steering committee.

### 2.1.4 Allied Health Professionals

The term 'allied health' covers a number of health professions including physiotherapists, occupational therapists, psychologists, dieticians and podiatrists working in both the private and public sector. These people play a key role in assisting clients in the community to manage their health and can assist in referring clients to a CDSM program.

## 2.2 Interventions

When developing self management interventions it is imperative that consumer input is utilised and key stakeholders are involved in creating or choosing the appropriate interventions (see Section 2.1.1). Both nationally and internationally, there are many disease-specific interventions offered to people with chronic conditions, however, only generic interventions will be mentioned here. Generic programs have shown to be more beneficial for people with multiple chronic conditions – both as a stand alone intervention and when used in addition to a disease-specific intervention. Awareness is also increasing that similar strategies can be equally effective in improving self management in different conditions (Davis & Wagner, 2000).

What also needs to be considered in the development of a CDSM program is the need for a variety of interventions to offer to clients at different stages of behaviour change (see Section 3). Not everyone is suited to one on one coaching or group programs – so it is best to have a selection of interventions on offer. There are a variety of self management interventions that can be made available to clients and a number of them will be explored in the following paragraphs.

### **2.2.1 Chronic Disease Self Management Program (Stanford Model)**

The Chronic Disease Self Management Program (CDSMP) was developed by Lorig, Gonzalez & Laurent at Stanford University Client Education Research Centre in the USA. It is a widely conducted workshop that has been shown to improve health behaviours (exercise, cognitive symptom management, coping, and communications with physicians), improve health status (self-reported health, fatigue, disability, social/role activities, and health distress) and decrease days in hospital (Lorig, Sobel, Stewart, Brown, Bandura, Ritter, Gonzalez, Laurent & Holman, 1999).

Several assumptions underlie this program:

- People with chronic conditions have similar concerns and problems
- People with chronic conditions must deal not only with their disease(s), but also with the impact these have on their lives and emotions
- Lay people with chronic conditions, when given a detailed leader's manual, can teach the CDSMP as effectively, if not more effectively, than health professionals
- The process or way the CDSMP is taught is as important, if not more important, than the subject matter that is taught (Lorig, Gonzalez & Laurent, 2006)

#### **Handy Hint!**

If using successful interventions from other areas remember to trial and localise it first.

#### **2.2.1.1 Workshop content**

The CDSMP workshop consists of six, two and a half hour sessions and covers the following generic information that can be applied to chronic conditions:

- Overview of self-management and chronic health conditions
- Making an action plan
- Using your mind to manage symptoms
- Feedback/problem-solving
- Difficult emotions
- Fitness/exercise
- Better breathing
- Pain
- Fatigue
- Nutrition
- Future plans for health care
- Communication
- Medications
- Making treatment decisions
- Depression
- Working with your health care professional
- Working with the health care system
- Future plans (Lorig, Gonzalez & Laurent, 2006)

#### **2.2.1.2 Venue**

Workshop venues need to be places where participants will feel comfortable and are conducive to learning. Community venues are often popular with mutual benefits for community organisations and the public.

## THINGS TO CONSIDER WHEN SELECTING A WORKSHOP VENUE

### Access

- Is the venue accessible by public transport?
- Is there wheelchair access and facilities for the disabled?
- Is there parking close by for clients who may not be able to walk long distances?

### Noise

- What is the noise level like?
- Is there an area which can be closed off from public access? (remember people may be disclosing personal information and participating in relaxation activities).

### Temperature

- Can the temperature be controlled to make the venue comfortable and to avoid exacerbations of certain conditions?

### Facilities

- Are tea/coffee making, toilet facilities available?
- Is seating provided?
- Is the area clean?

Community organisations often have space available for hire and may even see having a CDSM workshop held in their organisation a benefit to clients already attending the organisation, as well as increasing their community profile.

Be aware of situations where only certain groups may feel comfortable attending a community venue. For example, organisations established to provide a service to a particular cultural group or religion may not be appropriate as a venue for a CDSM workshop. People outside of that cultural/religious group may not feel comfortable attending for various reasons.

### WA Example

*The CDSM program in Perth has been run in a variety of settings in the South East region of Perth – including senior citizens centres, churches, community halls and the CDGP training room.*

### 2.2.1.3 Eligibility

The workshop is appropriate for persons with one or more of a range of chronic conditions such as diabetes, heart disease and arthritis. Participants generally should not be cognitively or psychologically impaired as this could impact on what they (and others) gain from the program. However, suitability for the course should be assessed on a case-by-case basis. It should be noted, however, that depression often tends to be a co-existing condition with chronic disease and clients with this condition should not be excluded.

Some organisations prefer to organise disease specific groups, whilst others operate generic groups, allowing the clients to self select. This is entirely a personal preference.

### WA Example

*Some organisations have chosen to hire CDGP to deliver the workshops for their own clients (eg. The Muscular Sclerosis Society). Others have preferred to be trained by CDGP (see Section 5) so that they can run their own workshops for their clients on an ongoing basis (eg. Community Physiotherapy at Royal Perth Hospital, WA).*

#### 2.2.1.4 Attendance

Workshops are best conducted with approximately 14-16 people. This number allows for sickness and attrition without impacting significantly on the group dynamics. Given unfortunate occasional absences of participants, it is hoped to have at least 10 in the group for each session which will allow everyone to enjoy the benefits of group interaction.

It is important to be flexible with client attendance to the workshop. If participants miss the first session, it is fine for them to start on the second session. However, if a participant will miss more than two of the six sessions, he or she should take the workshop at another time. It is important that the leader should encourage participants at the time of registration to plan to attend the whole workshop.

As mentioned previously in the manual, family/carers are important. In this particular workshop participants are encouraged to bring one 'support person'. When enrolling participants, it is a good idea for leaders to ask them if they will be bringing a support person to determine potential participant numbers. Support persons should sit with the group and participate as group members rather than just observing. Support persons gain just as much from the workshop as the regular participants as many sessions involve the caregiver and encourage their participation.

#### 2.2.1.5 Observers

Staff or other professionals may want to observe a workshop to gain a better understanding of the program. On these occasions, ensure that none of their clients are present in the group. It is generally best not to allow observers at the first or last session, as these are bonding and sharing sessions for participants. Workshop leaders should also ask participants for permission before allowing an observer to attend the session.

Directly observing a well run workshop is often the most effective way for someone to understand how the program is delivered and how it benefits clients. Health professionals, care managers, administrators or others who would benefit from a deeper understanding of the program, may find direct observation a very useful tool.

#### 2.2.1.6 Workshop fees

Charging a small fee for participants is optional. The following may inform any decision when deciding to charge participants for attending workshops:

##### *Advantages*

- May avert a high attrition rate
- May increase expectations of participants and increase participation
- People may be more committed to something they pay for
- People may value more what they pay for
- May contribute to cost of materials for running the workshop

##### *Disadvantages*

- A fee may be a barrier for someone who wants to attend the workshop but can't afford the fee

If the fee is a barrier to a participant attending the workshop, some organisations may choose to offer a number of free placements to clients in this situation.

### 2.2.1.7 Materials

Few materials are required to run this workshop. This program is designed to be a peer lead program and having fewer materials makes it easier to deliver. The few materials required to run the program include:

#### Charts

Charts are used in the workshop to emphasise key points outlined by the leaders. Usually the charts are positioned between both leaders so that participants can clearly read them whilst the workshop is being conducted. Leaders trained in facilitating the workshops are provided with the content of the charts in their leader's manual, so they can make their own charts for their own workshops. These charts do not need to be professionally produced, however they should be:

- Legible
- Readable – large print
- Durable – able to withstand wear and tear from continual use and transportation

#### Books

Participants should be provided with a copy of a book titled 'Living a Healthy Life with Chronic Conditions' (Lorig, Holman, Sobel, Laurent, Gonzalez & Minor, 2000) for the duration of the six week program. This book is a valuable resource for participants and can be referred to for additional information on topics covered in the workshop. Books should be made available to participants for the duration of the program. This can be done in a variety of ways. For organisations with a budget to run CDSM programs, books may be purchased, numbered and labelled and loaned to participants for the duration of the workshop. Another option is to approach local libraries to purchase the book so this is available for loan to community members.

Sometimes on completion of the workshop, clients will ask if they can purchase the books – so it is good to have a plan as to whether you would be the distributor of the books (i.e. have some stored particularly for selling) or whether you act as a conduit and refer them on to the publisher to order one themselves (James Bull Publishing – [www.bullpub.com](http://www.bullpub.com)).

### 2.2.1.8 Leaders

Workshops are facilitated by two leaders who have been trained in this model (see Section 5.1). Leaders run the group as equals to the rest of the participants and ideally, at least one leader – if not both should have a chronic condition.

### 2.2.1.9 Promotion

When scheduling workshops, consider holidays, traffic and weather in your area. The best time for daytime classes is between 10:00am and 4:00pm weekdays. If possible, some evening or weekend workshops could be offered (budget permitting) for those people who work. Whichever group of people you are planning to run groups with, it is best to find out what time is more suitable for them. Experience has shown that mornings are more popular as people with some chronic conditions tire easily and prefer to rest in the afternoons. However, people with arthritis often find mornings to be quite difficult, hence preferring the afternoons to attend the workshop.

The workshop can be promoted in a number of different ways to attract participants:

- Placing an article in the local paper – this will often generate a good response from interested community members. When submitting an article, it is often a good idea to include positive quotes from previous participants which demonstrates how they benefited from attending the workshop. Be clear about what the workshop will involve and the time commitment expected of participants. Remember to explain the term chronic condition and use examples of well known chronic illnesses such as diabetes, heart disease and arthritis. It is not uncommon to find people with chronic conditions in the community who do not recognise themselves as having a chronic illness nor understand what the concept means.

- Using brochures or flyers – these can be distributed to medical practices and other health organisations. They can be handed to people by either their health professional, or picked up from the waiting room by the person themselves.

Remember to use layman's terminology on all client promotional materials to prevent confusion and misunderstandings about the program. A client's first contact about the program is most likely to be from reading either an article or brochure and it's important that they have a clear understanding of who the workshop is for, what it involves and how they can benefit. Include a contact phone number on all materials to allow clients to call and ask any questions they may have. It may also be worthwhile to develop a brochure for GPs and health professionals which describes the workshop from a practitioner's point of view and includes information on how they can refer their clients into the program.

Referral from other health programs is an excellent source of participants for workshops. Participants who have already completed health programs such as a cardiac rehabilitation program, respiratory clinic or diabetes education program are often interested and at the appropriate stage to join a self management program. These health education programs tend to focus on teaching participants about their specific chronic condition but do not equip them with self management skills. Attending a self management course following an education program is thus an ideal progression for people with chronic conditions. This referral pathway can generate a large and regular intake of clients and has the lowest attrition rate.

To make use of this referral pathway, identify programs within the community which offer health education to clients with chronic conditions. Establish a relationship with the program coordinator and develop a process whereby participants are invited to join a CDSM workshop upon the completion of their health education program.

Promotion can also occur in the form of a presentation to interested health organisations by a CDSM program staff member. Information presented can include what the workshops are about, how they are conducted and who is eligible to attend. This helps to increase knowledge of what CDSM is and raise awareness of the self management programs that are available.

#### **2.2.1.10 Recruiting participants**

The most effective recruitment tool at most sites has been by direct invitation to people who have done or are doing other programs and support groups aimed at disease management. Other methods include advertising in the local paper and advertising via flyers and brochures at GP surgeries.

#### **2.2.1.11 Enrolling participants**

The health professional or staff member allocated to coordinating the workshops should follow an enrolment process which includes collecting all relevant details from participants such as their address and contact details. These details will be useful if the workshop coordinator or facilitators need to contact participants for any reason such as a delay in the commencement of the workshop.

#### **2.2.1.12 Participant withdrawal**

You will need to determine your local dropout pattern and plan your enrolment strategy accordingly. If dropout is consistently high it may be worthwhile to enrol a few extra participants. Fewer participants will result in poor group interactions and participants will not benefit from the workshop as much as they would have if the group was larger. Some of the common reasons for participant withdrawal are illness, conflicting health appointments, family issues and also finding that the workshop is not suitable for them.

## 2.2.2 Chronic Disease Support Group

Managing a chronic disease can often be stressful and isolating and finding an appropriate support group may help. Peer support is an essential component of CDSM. Research has shown that many people with chronic conditions find it difficult to continue with healthy lifestyle behaviours outside the structure of a supervised program and do not maintain behaviour change once participation in a structured program has ceased. Establishing a chronic disease support group is an excellent way to facilitate ongoing and regular self management and health lifestyle behaviours for those people who want to change but lack the capacity or motivation to do it by themselves.

A support group provides clients and their families with a social framework for promoting positive adjustment to their condition and seeks to improve client's quality of life. Support groups offer clients and their families the opportunity to meet and share their strengths, experiences and knowledge related to their common problem. Literature has shown that individuals attend support groups for six main reasons:

- to secure more information
- to learn how to cope with symptoms
- to talk to others who understand their symptoms
- to pursue the belief that only another person with the same disease truly understands how they feel
- to deal with symptoms that frighten them and to derive enjoyment helping others help themselves (Scordo, 2001; Lesham, 2003)

Support groups have also been shown to be beneficial for a number of chronic conditions including cancer, heart conditions and chronic pain (Smeardon, 2001; Stewart, Davidson, Meade & Hirth, 2002; Houtzager, Grootenhuis & Last, 2001; Subramaniam, Malcolm, Stewart & Smith, 1999).

Local evaluation for the WA CDSM program has shown that participants of CDSM support groups highly value the opportunity to learn more about their health and interact with others who have similar conditions. Keeping the focus on what members would like to hear more about and encouraging community ownership of the group are key elements for the success of the support groups.

### 2.2.2.1 Aim

A CDSM support group aims to help participants increase their knowledge in a variety of health issues in a social, non-threatening and caring environment. A support group also provides a forum for participants that allows them to interact and meet people in similar situations and who also have an interest in learning more about improving their health condition. The friendly nature of a support group encourages members to share their experiences and problems with fellow members and together identify solutions. This exchange of information with others who have similar concerns and problems fosters a sense of self esteem and confidence in participants and helps them to address issues arising from their own health condition.

A chronic disease support group may also:

- Aid in identifying further barriers to self managing health within the target group
- Increase members of the target group feeling of control over their lives
- Provide community education and awareness of health and social issues
- Provide an opportunity for social networking
- Provide a motivational tool for the target group to manage their lives
- Promote the use of goal setting in one's life
- Promote the idea that the target group has the capacity to play an active role in the management of their health
- Recognise that the target group are differently placed with regard to their readiness to self-manage (stages of change)
- Foster a culture of active participation by individuals in the management of their own health
- Promote self management in the community
- Encourage the target group to work in close partnership with their GP and health care professionals to achieve maximum health and quality of lifestyle benefits

### 2.2.2.2 Location of support group

The location of a CDSM support group can be determined by conducting a simple needs assessment. It can be helpful to consult with local health and social services and health professionals working in the community to source essential information such as:

- Is there currently a CDSM support service being offered?
- Are there other programs to link in with? There may be an opportunity to cross promote services.
- Views on the benefits, barriers and feasibility of implementing a CDSM support group.
- Background and historical information on the community which may have influencing factors on the success of the program.

Holding a focus group made up of members from the target population living within the area selected for a CDSM support group is a useful strategy to ensure that the program meets the community's needs. Client feedback is invaluable and will provide useful information on what community members would like to receive from attending a support group.

Helpful information from clients may include:

- Information on health and non-medical issues which may affect their lives
- Suggestions for a suitable venue in the area
- How often the group should meet
- What days and times are practical and convenient, (eg. avoid holding meetings on pension day)
- If a committee should be set up to run the group
- How involved they would like CDSM program staff members to be

### 2.2.2.3 Venue

Having a comfortable and accessible venue for a support group is a key factor in making the program a success. A good source of information when seeking venues is your local council. Reduced hire fees are often made available for senior and community groups that are not for profit.

Some helpful hints are to:

- Include a map marking the location of your venue on all promotional materials
- Indicate if and where parking is available
- Provide details of the nearest public transport service
- Offer information on local community transport services
- Inform clients of any costs involved
- Provide signage with the name of the CDSM support group at the venue

To avoid confusion and to limit participant anxiety on their first visit to a support group, it is important to ensure that clear and concise instructions are given regarding the location of the group. Remember to make it clear to participants that they are welcome to bring along a support person, such as a family member, friend or carer.

## THINGS TO CONSIDER WHEN SELECTING A VENUE

### Access

Is the venue accessible by public transport?

Is there wheelchair access and facilities for the disabled?

Is there parking close by for clients who may not be able to walk long distances?

### Noise

What is the noise level like?

Is there an area which can be closed off from public access? (remember people may be disclosing personal information and participating in relaxation activities).

### Temperature

Can the temperature be controlled to make the venue comfortable and to avoid exacerbations of certain conditions?

### Facilities

Are tea/coffee making, toilet facilities available?

Is seating provided?

Is the area clean?

### 2.2.2.4 Promotion

There are a number of ways to promote a CDSM support group to increase awareness and attract participants from the local community. In the early stages of developing the support group, promotion will play a key factor in recruiting group members. Therefore, the initial levels of promotion can be expected to be considerably higher than ongoing and maintenance promotion.

#### Initial promotion

It is important by this stage to have a clear understanding of who the target population is. The promotional strategy should appeal to the target group and demonstrate why they will benefit from joining a support group. Community consultation with the target population focus group and health professionals will play a key role. An advertising campaign should be developed in close consultation with these sources to ensure that relevant messages are conveyed to the target population about the support group.

Types of promotion used to market a support group can include:

- Paid advertising in the local or community paper (See Figure 4 for example)
- Distribution of flyers, brochures and posters within the community (library display, recreation and leisure centre, medical practice waiting rooms, community health building, local government building, senior citizens centre etc).
- Feature article in the local paper or community paper
- Feature article in special interest paper (eg. for seniors – Have a Go News)
- Paid advertising in special interest paper (eg. for seniors – Have a Go News)
- Radio community announcement
- Verbal promotion of the group at other events or programs
- Through any other programs your organisation may conduct
- Invitations – At the first meeting of a CDSM support group it is useful to develop a registration list with the name and address details of people who are interested in attending the group. Regular invitations can then be sent out to those on the registration list with the details of each upcoming support session. As new members join the group they can also be added to the mailing list.
- Display boards at local health events (eg. Stay on Your Feet week)

**WA Example**

In 2003, the Health Partners Chronic Disease Self Management Program implemented a community intervention known as the Live Life Club as part of the Commonwealth-funded Sharing Health Care Initiative. The Live Life Club was a chronic disease support group which aimed to promote awareness and understanding of self management to participants and to build their capacity to apply the principles of self management to their lifestyles.

The Health Partners program staff consulted with community health professionals and members of the target group to develop an effective advertising campaign promoting the Live Life Club as a chronic disease self management support group. This consultation led to the creation of an advertising campaign which featured two cartoon characters named Joy and Phil. Joy and Phil embodied many of the characteristics that were common to the Health Partners program target group with the expectation that members of the target group could identify with them. Their stories featured the same issues that people with chronic disease faced every day such as frustration about not being able to do what they used to do. The comic strip provided a common recognisable theme in the advertising campaign. The message of the comic strip changed from week to week to maintain reader interest and communicate different important messages. The comic was intended to be visual, simple, non-prescriptive and engaging. It also featured local events and recognisable local characters to give it a local flavour. The comic helped to distinguish the Live Life Club advertising from other advertisement and appeared in the same place of the local community paper every week to encourage regular readership and awareness.

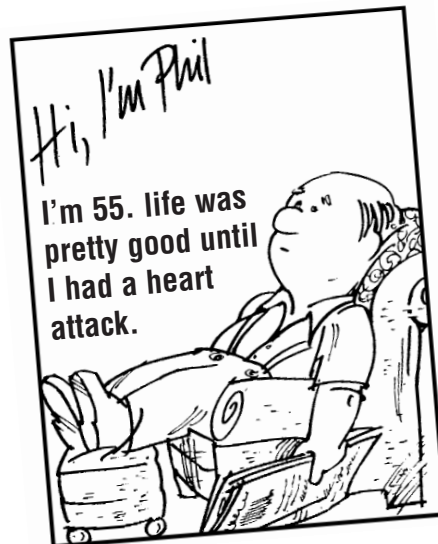
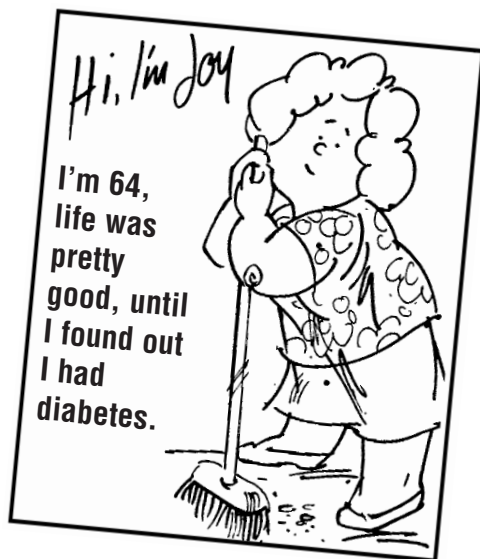




Figure 4: Live Life Club Community Newspaper Advertisements

### Ongoing promotion

Once a support group has attained a regular number of attendees, the level of promotion may be reduced. The first level of promotion to discontinue is paid advertising. This is because it is usually quite expensive and it is not a sustainable payment for a support group. This is a positive step. It reduces costs and increases the sustainability of the group by the fact it can successfully continue without having to rely on paid advertising.

While attendances may be regular, it is important not to halt all promotional measures. Although the group is established it is still essential to attract a regular flow of new members to counteract the natural attrition rate of the group. Without having to rely on paid methods of advertising there are other options to consider such as:

- **Feature articles** – Local newspapers are often more than willing to accept an article about a support group at no cost. Ensure the article submitted to the paper is promoting an interesting event such as the first anniversary of the support group or a special guest speaker. The use of inspiring and motivational quotes from group members and an interesting photo will also increase the likelihood that the article is accepted and placed in a prominent location within the paper.
- **Health professionals** – Asking local health professionals who work with clients from the target group to encourage them to attend the support is an excellent form of ongoing promotion. Clients are also more likely to attend the CDSM support group if it is recommended by a health professional.
- **Flyers** – Distribute to community venues
- **Invitations** – Continue to send out invitations to the support group members on the registration list with the details of upcoming meetings. You may wish to decrease the frequency of mailing out the invitations to reduce administrative task time, reduce costs and move another step closer to group sustainability.

**WA Example**

*Invitations to the monthly Live Life Club meeting were sent out at the start of every month. This has now been decreased to sending out an invitation every two months with the details of both meetings being included on a single invitation.*

**2.2.2.5 Meetings**

The focus of a CDSM support group meeting is to address the needs of the group and encourage the adoption of self management principles. An idea for the first meeting of a support group is to hire a motivational speaker to empower clients to share their health care issues and to raise enthusiasm for the support group. The speaker can brain storm with the clients about what some of the medical and non-medical issues are for people with chronic conditions. This will generate a list of possible presentation topics for the future (see Figure 5 for examples of topics generated for the Live Life Club in WA).

**Handy Hint!**

Build capacity in your clients – give them the knowledge and tools to take control of their health.

**2.2.2.6 Ownership**

Establishing ownership is an important step in making members feel like they belong to and are responsible for a support group. A sense of ownership of the group by its members will result in regular attendance and will generate interest in the group's future.

Group ownership can be achieved by ensuring that the group is run according to the needs of its members. Members should be regularly asked to share what they would like to gain from attending their CDSM support group and what topics and issues they would like to learn about. Topics can be anything that impacts on member's day to day living with a chronic disease. Expect to receive requests for both health and non health topics as it is not only medical problems that have an impact on health but also social and economic issues. This process of asking for feedback from participants should occur at least every six months to ensure that the session content is meeting members' needs.

Using the information that the support group members provide, expert and reputable speakers should be sourced to deliver accurate information. Ensure that speakers have appropriate qualifications and expertise in the topic they are presenting. Ask speakers to bring along any relevant resources such as brochures or booklets for the group's members to take home and allow plenty of time for participants to have the opportunity to ask the speaker questions.

**WA Example**

*Live Life Club requested topics – some examples:*

<i>Pain management</i>	<i>Cardiopulmonary resuscitation</i>
<i>Food for health</i>	<i>Safety for seniors</i>
<i>Managing your medications</i>	<i>Continence</i>
<i>Arthritis</i>	<i>Optometry</i>
<i>Public transport for seniors</i>	<i>Estate planning wills and power of attorney</i>
<i>Stress management and relaxation</i>	<i>Local government services for seniors</i>
<i>Managing asthma</i>	<i>Fall prevention</i>
<i>Tai Chi</i>	<i>Funeral preparation</i>
<i>Diabetes</i>	<i>Natural therapies</i>

Figure 5: WA's Live Life Club requested topics for presentation

### 2.2.2.7 Meeting format

Once a day and time have been chosen for a support group, the format of the session must be decided. Some general considerations are:

- Avoid holding a support group meeting for more than two hours as a longer length of time may be uncomfortable for people with certain health conditions.
- Be at your venue at least 30 minutes prior to the start of a meeting. This will allow enough time to set up and be ready to welcome members as they arrive.
- Ensure adequate staff members are present to coordinate meetings – there may be too much for a single person to complete.
- Ensure members register as they arrive.
- Welcome the speaker and ensure they have everything they need for their presentation.
- Introduce the speaker to group.
- Include a refreshment break midway. Ensure that the refreshment break is at least 20 minutes. Social interaction is a key factor of a support group and members should be encouraged to talk to one another and welcome any new members.
- Make sure your refreshments reflect the healthy lifestyle you are promoting. For example, provide a fruit platter or healthy biscuits alternatives (contact Diabetes WA for advice on appropriate biscuits).
- Ensure there is ample time for questions.
- Thank the speaker and members for coming and close the session with the details of the next meeting.
- Clean and lock up venue – encourage members to help.

### 2.2.2.8 Costs

Asking participants of a support group to contribute towards costs is optional. Higher costs such as the hire of the venue, advertising and administration costs are best borne by an organisation. Other costs such as the purchase of refreshments may be something which members would be willing to contribute towards. Asking for a gold coin donation upon entry or a yearly subscription fee are options to consider.

**WA Example**

*Members of the Live Life Club pay a gold coin donation upon entry. As a further incentive, members are entered into a raffle prize draw which is drawn at the end of each meeting. The number of raffle tickets they receive is based on how much they have paid, eg. \$1 coin donation equals one raffle ticket while a \$2 coin donation equals three raffle tickets. The money collected goes towards purchasing fruit, biscuits and beverages for morning tea and the raffle prize draw prizes. Two prizes are handed out at the end of each meeting worth about \$10 each. Having a raffle prize draw is an added attraction which helps to draw people to the meetings and is a fun way to conclude each session.*

**2.2.2.9 The roles and functions within a CDSM support group**

In the early stages of establishing a support group, many of the administrative and room set up tasks must be coordinated by program staff members. Over time, regular attendees that are willing and motivated may be identified and asked to help out. To build group sustainability, group members may also be asked to perform tasks at meetings on a regular basis. When this stage has been reached, a committee should be established.

The establishment of a committee should be a transparent process within a support group to avoid any conflict and personal bias. The selection of committee members should occur through a process of nomination by the group's members followed by voting at a group meeting. Avoid bypassing this process and personally selecting members for the committee. Allowing the group to select their own committee is another process which helps members develop feelings of ownership toward the support group.

**Handy Hint!**

Keep in mind: How can this intervention be sustainable? Build sustainability into all stages.

Before selecting the committee, ensure that support group members have a clear understanding of what the role of a committee member is. Members should be made aware of the time commitment required and given a description of the tasks to be performed by committee members. Becoming a committee member is purely a voluntary position and any member who would like to resign from the committee should be able to do so at any time. The process of selecting committee members should also be reviewed at least once a year to avoid committee fatigue.

Roles that may be performed by committee members include:

- Room set up coordinator (1 or 2 people)
  - Duties:**
    - Arrive 30 minutes before the sessions starts and open venue
    - Set up kitchen facilities
    - Set up tables and chairs
    - Lay out health promotion resources (Having brochures and flyers on different health issues available can be beneficial for members)
    - On departure, lock up venue and return furniture to its original position
- Morning coordinator (1 person)
  - Duties:**
    - Meet with speaker and ensure they have everything they need for their presentation
    - Introduce speaker to the group
    - Coordinate the format of the meeting (refreshment break and close of meeting)
    - Thank speaker
    - Arrange the drawing of the raffle prize if applicable
    - Additional speaking duties and announcements as required

- Kitchen coordinators (2-3 people)
 

*Duties:*

  - Set up cups and saucers on arrival
  - Lay out food and utensils during refreshment break
  - Make coffee and teas as required during refreshment break
  - Do dishes and clean up kitchen

*Materials:*

  - Purchase perishable refreshments prior to the meeting using money collected from the group (fruit, biscuits, milk and juice)
  - Bring tea, coffee and sugar to meeting
- Meet and greet coordinator (1-2 people)
 

*Duties:*

  - Welcome members as they arrive to the meeting
  - Mark names off the registration list
  - Add the details of any new members to the registration list
  - Collect money and distribute raffle tickets – if applicable
- Welcome coordinator (1 person)
 

*Duties:*

  - Talk to and make comfortable any new members that may arrive
- Other committee duties
  - Help other committee members with their tasks as required. If no help is needed, socialise with the group.

Be mindful not to take committee members for granted. Regular meetings should be held with committee members to touch base and address any issues that arise. This doesn't need to be a formal event but can be a short 15 minute session before or after a support group meeting. Encourage members to offer feedback and make it clear that they are always welcome to make contact via the phone if they need support. Hosting a luncheon, outing or dinner for the committee members annually is also a nice way to show your appreciation for the time and effort committee members have contributed throughout the year.

### 2.2.2.10 Evaluation

To ensure that the support group is meeting the needs of participants, it is important that regular evaluation takes place. The best way to do this is by a feedback (evaluation) form. These can be handed out at the end of each session asking what members thought of the day's activities. Questions that could be asked include:

- Was it interesting?
- Was it useful to you?
- Do you like the way the morning was organised?
- Did you like the venue?
- What did you like best about today's activities?
- Would you come again? If no, can you tell us why?
- Do you have any other comments or suggestions that may be useful?

### 2.2.3 Walking Group

A walking group is an easy, low cost and sustainable CDSM intervention to offer people in the community with chronic conditions.

An intervention such as a walking group is an excellent way to support and encourage clients with chronic disease to build fitness, increase social activity and maintain health. The following paragraphs document how a community walking group for seniors can be successfully established as a sustainable program.

**WA Example**

*The Health Partners team established two walking groups called the 'Healthy Heart Walkers' with the purpose of providing a healthy lifestyle maintenance program for clients with chronic conditions. Members from the support groups in Gosnells and Belmont played a key role in establishing the walking groups.*

**2.2.3.1 Why establish a walking group?**

Research has shown that many people with chronic conditions find it difficult to continue exercising outside the structure of a supervised program and do not maintain regular exercise once participation in a structured fitness program has ceased. Establishing a community walking group is an excellent way to facilitate ongoing and regular exercise for those people who enjoy exercise in a group setting but lack the capacity or motivation to exercise by themselves.

Regularly attending a walking group can provide people living with a chronic condition with many benefits. Regular exercise increases muscle and bone strength, joint function, improves cardiovascular function, controls body weight, decreases blood pressure, reduces the likelihood of a fall and can positively impact on self-esteem and stress levels. In addition to these physical benefits, attending a walking group provides an opportunity for social interaction and the chance to meet people who are experiencing similar health issues (Bauman et al, 2002).

Self management skills can also be learnt and built upon by attending a walking group. Watching others successfully make decisions regarding their exercise can act as encouraging examples to those who are less advanced in this area. Clients can learn how they can adjust their exercise routine as needed for changes in disease activity, pain, weather and scheduling conflicts (Minor & Lane, 1996).

**2.2.3.2 Needs assessment**

Before implementing a walking group, a needs assessment should be conducted. This can include a review of literature, a review of other walking programs in the community and consultation with health professionals and consumers. Conducting a needs assessment can provide valuable information on the needs and priorities of the population and draw attention to areas that have limited health resources and services (Wright, Williams & Wilkinson, 1998).

Consultation with members of the target group and relevant local health professionals can be an important source of information (Wright, Williams & Wilkinson, 1998). It can be a useful tool in identifying barriers which may prevent the target group from participating in the walking group. Other information gained from community consultation may include background information on the community which can reveal factors that may influence the success of the walking group. Some factors which may limit involvement in community exercise programs include:

- Cost
- Availability of transport and parking facilities
- Time
- Suitability of program for people with chronic illness or rehabilitation needs
- Seats to rest
- Toilets
- Shade/shelter (especially at the start and finish of a walk)

### 2.2.3.3 Planning

When commencing a walking group in the community, it is important to prepare a list of objectives the walking group is expected to meet. This will help give some focus toward the planning of the group and will also provide a basis against which the group can be evaluated. Some sample objectives may include:

- Increase participants' involvement in regular exercise
- Increase participants' fitness and ability to exercise
- Improve participants' self-esteem
- Reduce participants' stress levels
- Provide an opportunity to exercise in a safe and accessible environment
- Provide an opportunity to exercise which is affordable and accessible to members of the community
- Encourage participants' capacity to perform self-directed exercise (eg. encourage participants to join other fitness programs or to do additional exercise on an individual level)
- Increase participants' self-efficacy of their health (eg. make participants more aware of their health status and ways they can improve it)

Feedback from consumers about the walking group's objectives will be valuable to determine whether they are realistic and achievable. Other things to discuss with a consumer focus group should include:

- The walking groups meeting point
- The designated walk and if there are alternative walks available to prevent boredom
- How often and on what days the walk should be held
- What time of day the walk will be held
- If there is a cost involved and if so, how much
- Who should lead the group
- Who is eligible to join the group

When selecting the route to be followed by the walking group, it is important to consider that walkers of varying fitness levels are most likely to be present. Try to select a route which offers a longer option for faster walkers and a shorter option for less capable walkers. If possible, try to arrange it so that all walkers finish at the same time and in the same location.

### 2.2.3.4 Sourcing a consumer focus group

Sometimes it can be difficult to access consumers who are both interested in the program and willing to contribute their time to ensuring that the program meets the community's needs. Some ways to access these people can include:

- Placing an advertisement in the local paper describing the program and asking for volunteers for a focus group.
- Publishing an article outlining the aim of the program and invite interested readers to help contribute by joining a consumer focus group.
- Distributing a flyer in areas that the target population is most likely to frequent (eg. Focus group participants for a seniors walking group program may be sourced from the local senior citizens centre).
- Asking for volunteers from other programs which your organisation may coordinate for the target population.

Members from the focus group are often those people in the target population who have a strong sense of community and will make excellent founding members for the walking group. Involving them in the planning stages will serve as encouragement for them to actually attend the program when it is established.

### 2.2.3.5 Recruiting walkers

When recruiting people to the walking group it is essential to remember that in order for a person to change their behaviour, they must first recognise that there is a relevant reason for them to do so. Therefore, when promoting the walking group, it is important to endorse all the positive benefits people can gain by attending the group. People are more likely to adopt an activity when they expect to receive rewards such as increased energy levels, feelings of wellbeing, weight control and increased fitness (Pert, 1997). A walking group is also an ideal option for people seeking social interaction and the opportunity to make new friends. Having social support is an important factor for people to start and maintain an exercise activity (Resnick et al, 2002).

Before recruiting walkers there should be a clear understanding on who the group caters for and if walkers must meet certain eligibility criteria before attending. For example, if the walking group was established for people with chronic conditions as a way for them to increase their fitness and promote self management skills, then it may not be appropriate to allow members of the general public without a chronic condition to attend the walking group. To avoid any potential conflict about walkers' suitability to join the group, think carefully of appropriate avenues to follow when recruiting walkers. A walking group for people with chronic conditions may attract walkers from health programs of limited duration such as cardiac rehabilitation programs and diabetes education classes. If you choose to advertise your walking group in the local paper or through the use of flyers, remember to be clear on who the walking group is for.

### 2.2.3.6 Walk leaders

Selecting walk leaders is an important part of a successful community walking group. Leaders should be community members who are willing and capable of fulfilling the requirements of a walk leader. Walk leaders should also be individuals who demonstrate strong self management skills and are able to act as positive role models to others in the group.

Before allowing community members to lead a walk, it is important that they attend walk leader training. The Injury Control Council of Western Australia (ICCWA) has developed a walk leaders training manual as part of the Stay on Your Feet WA program. This manual can be accessed from their website, [www.iccwa.org.au](http://www.iccwa.org.au).

The walk leader training manual is only for the use of organisations establishing walking groups and is not for the use of individual community members. For further advice on the use of this manual, please contact the ICCWA.

Information incorporated in this manual includes; the role of the walk leader, health and safety, risk management, stretching and warm up exercises, injury first aid and examples of useful forms to assist walk leaders such as a registration form and attendance list.

### 2.2.3.7 The path to sustainability

It can be quite difficult to attract enough people to have a well functioning and sustainable walking group. The three main things to be addressed regarding sustainability are:

#### **1. Keeping up the level of interest in existing walkers**

Maintaining group interest is dependent on a number of things. The most important element is the social interaction and the sense of belonging to a group. Once people have belonged to a group for a while they stop thinking of the walking group as an exercise group and start thinking of it as a social group. They will attend each week to see their friends and chat; it just so happens that they exercise at the same time. For this to take place the leadership is very important. Walk leaders should greet new people and make them feel welcome; they should also be included in any extra activities that the group organises. If the newcomer is not embraced by the group and made to feel welcome, they are most likely to leave. The social aspect for all members can be enhanced if the group organises a morning tea following the walk every now and then or even weekly if the group desires.

**Handy Hint!**

Warmly welcome any new members and make them feel that they are an important part of the group. This will increase the chance they will continue to attend.

Another method to ensure people continue to attend is variety. It is good to choose venues that have different routes the walkers can take. For safety and logistic reasons, it is important to start and end the walk at the same place each time, but if the route in between can be varied then this will make walkers (particularly the stronger faster walkers) more interested in coming back. Once in a while the group might arrange to meet at another location for a change. Organising an occasional bus trip excursion or lunch will improve the social aspect of the group and will help retain member interest in the walking group.

**2. Recruiting**

The best way to attract new walkers is by personal invitation. If a person is personally invited to join a group there is a greater chance that they will attend than by any other method. A lot of people find it difficult and perhaps awkward being the new person in a group. A positive and non-threatening way to attract new members is to hold 'one off' promotional events hosted by the existing walking group. An example of such an event would be to host a walk during the national promotion of a well known health condition such as Diabetes Week or Heart Week. The walking group's event can be heavily promoted through flyers and the newspaper as an opportunity for seniors to attend a walk supporting a good cause. New people will be more willing to go to an event such as this as they won't feel like they are the new person in an existing group, but one of many people attending an event. It is important for the walk leaders and program coordinator to use this opportunity to chat with these people and encourage them to attend the regular walking group.

**Handy Hint!**

People are more likely to attend a walking group if they have been personally invited by one of the group's members. Encourage walking group members to do this!

The next best recruitment method after personal invitation is by group invitation. If there are any other chronic disease type programs in the area, talk with the coordinators of these programs and try to get them to encourage their members to attend the walking group. Program participants can be encouraged to attend the walking group by incorporating a trip to the walking group as part of their program, asking a member of the walking group to come to the program to talk about the group or by handing out flyers about the group.

For those with easy access to general practice such as a Division of General Practice, messages can be sent to GPs and practice staff to encourage their clients to join the group. The weight a GP's message carries is enormous, but referrals from GPs should not be relied on, as they have many competing programs or options for their clients. Another method is to put an advertisement in the local paper however this can be expensive. A more effective and affordable option is to place a free feature article in the local paper that may talk about the benefits of physical activity and the availability of the walking group. Distributing flyers and brochures in waiting rooms of general practices, community health centres, libraries and so forth, is another form of promotion that can be utilised for the walking group.

**3. Supporting the walk leaders**

Walk leaders are the most valuable asset of the group. It is through the leaders that the members will feel they have ownership of the group. Once the group has self ownership it is well on its way to being successfully sustainable. When members start talking about 'our' group rather than 'the' group or 'your' group, they are demonstrating feelings of ownership. Walk leaders need to be valued, listened to and be allowed to make decisions for the group. Remember to hold regular feedback sessions, host a thank you event annually and generally let them know that they are making a vital contribution to the success of the walking group that is hugely appreciated.

**Handy Hint!**

A group with well supported, happy and committed walk leaders will be a cheerful and social group that people will want to keep coming to.

**2.2.3.8 Resources for walking groups**

The Western Australia Government Department for Planning and Infrastructure has several useful walking resources that can be accessed by visiting their website [www.dpi.wa.gov.au/walking](http://www.dpi.wa.gov.au/walking)

Resources include:

- A list of some of the most popular walks in Western Australia  
[http://www.dpi.wa.gov.au/mediaFiles/walking\\_where\\_to\\_walk.pdf](http://www.dpi.wa.gov.au/mediaFiles/walking_where_to_walk.pdf)
- Local walking maps  
<http://www.dpi.wa.gov.au/travelsmart/14972.asp>
- Information and contact details for West Australian Walking Groups  
[http://www.dpi.wa.gov.au/mediaFiles/walking\\_walking\\_guide06.pdf](http://www.dpi.wa.gov.au/mediaFiles/walking_walking_guide06.pdf)

**2.2.4 Other CDSM Interventions To Think About**

There are many different interventions that can be considered when developing a CDSM program. Again, the types of interventions chosen will depend on what key stakeholders see as an appropriate strategy to implement. Be flexible, sometimes gaps and issues are only revealed by the process of implementing an intervention and it may be necessary to make changes to the interventions offered.

**WA Example**

*During the delivery of the one on one facilitation intervention whereby facilitators went out to 'coach' clients, it was discovered that significant knowledge gaps in the community were present in regards to nutrition education. This led to the development of nutrition workshops specifically tailored to suit particular conditions. Clients were then directly referred into the specific dietary workshop that suited them.*

**2.2.4.1 Pedometer programs**

Pedometer walking programs are currently popular throughout Australia. Most programs in existence at present are loosely based on the original Rockhampton 10,000 steps program, which emphasised the need to walk 10,000 steps a day to achieve a healthy lifestyle. Using this program as a concrete base, other programs have used the pedometer in their CDSM programs as more of a motivational tool to their clients emphasising that they would benefit even from the smallest increase in steps.

**WA Example**

*The Health Partners program named their program 'Every Step Counts' because every step did count! Most of the clients in the program would have had trouble meeting the 10,000 steps a day goal – but even doing a few more extra steps each day was a great goal for them to set.*

**2.2.4.2 Nutrition workshops**

Another option for a CDSM program is the provision of nutrition workshops for clients with a chronic condition. The aim of such interventions is to improve the client's knowledge of nutrition in the management of their chronic condition.

Workshops should be developed by a dietician or nutritionist who specialises in the types of conditions dealt with by the program. For example, if the program targets those with type 2 diabetes a workshop could be developed that incorporated nutritional information particularly relevant for diabetes clients. Workshops may also be generic to all chronic diseases and could cover all (or some) of the following areas:

- Providing participants with a rationale for and skills to modify their eating patterns as part of learning to maintain (or attain) a healthier lifestyle and enhancing the management of their condition.
- Providing participants with an opportunity to apply recommended dietary practices that assist to maintain (or attain) a healthier lifestyle and enhancing self management – such as cooking classes.

### **2.2.4.3 One on one interventions**

It is important to remember that not all clients are ready to, are unable to, or want to attend 'group' type interventions. These clients are usually 'pre contemplators' or have other socioeconomic barriers that prevent them accessing these programs. Often, this group of clients miss out on the benefits of such interventions. Depending on funding and resources (as this is requires a large amount of both), a one on one facilitation or 'coaching' type intervention should be considered.

The objective of such an intervention is to encourage clients to achieve awareness about their condition, their lifestyle and barriers to a healthy lifestyle. It also aims to increase the client's knowledge of services available to support self management.

The level of facilitation needs to be determined by the client's stage of change or readiness to change. This type of intervention includes:

- Meeting with the client at the general practice/home to determine facilitation (or coaching) needs. Using the Flinders CDSM tools to assess self management capacity would be the most suitable approach (see Section 5.2)
- Regular phone calls to monitor the client's progress
- Development of action plans (same format as care plans)
- Referral to existing services
- Assisting of clients to deal with their social barriers to health (social determinants of health), rather than just focusing on medical issues

It is important in a CDSM program, to avoid case management, but rather promote self management by facilitating clients through this process. Clients should then be referred to existing services in the community or one of the other types of CDSM interventions that are offered by the CDSM program.

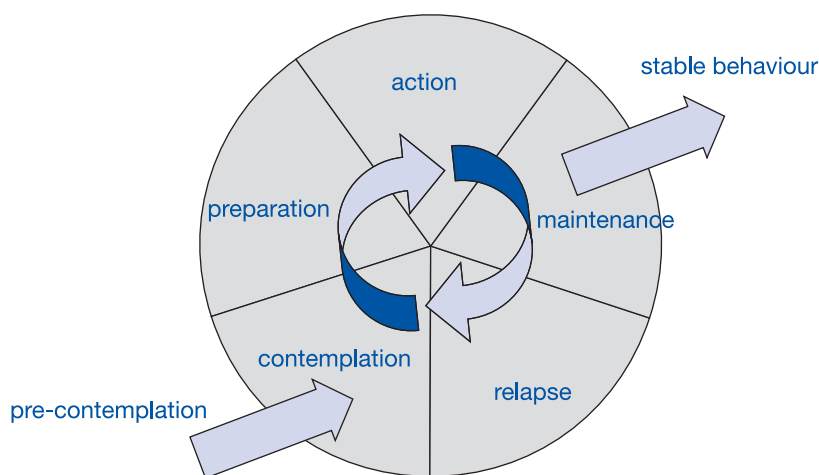
### 3 Stages of Change Model

Helping clients change behaviour is an important role for health professionals and is the underlying role of a CDSM program. All the interventions mentioned in Section 2 have been developed to aid and support clients in adopting new health behaviours that will help them live longer and healthier with their chronic conditions. It is important, however, in the development of and referral into interventions, that there is an understanding by health professionals of a client's readiness to make change, recognising the barriers to change and helping clients anticipate relapse (Zimmerman, Olsen & Bosworth, 2000). When developing a CDSM program, it is imperative to recognise that clients are in different stages of change of behaviour and that a 'one size fits all' attitude cannot be taken to behaviour modification by referring them into an intervention that they may not be ready for.

The Stages of Change model was originally developed in the late 1970s and early 1980s by Prochaska & Di Clemente when they were studying how smokers were able to give up their habits or addiction. This model has been applied to a broad range of behaviours including weight loss, overcoming alcohol and drug problems. The idea behind the model is that behaviour change does not happen in one step, but rather with people tending to progress through different stages on their way to successful change. This progression is very individual and happens at different rate for everyone (Kern, 2005). The model also explains why some interventions are not suited for everyone, and why people should not be coerced into taking part in some interventions when they are not ready yet. In fact, it could be counterproductive if one person is forced to change a behaviour when they are not quite ready.

The Stages of Change model shows that for most persons, a change in behaviour occurs gradually, with the client moving from being uninterested, unaware or unwilling to make a change (pre-contemplation), to considering a change (contemplation), to deciding and preparing to make a change (preparation), to genuine determined action is then taken and over time, attempts to maintain the new behaviour occur (action), to maintaining the new behaviour (maintenance). Relapses are almost inevitable and become part of the process of working toward life-long change (Zimmerman, Olsen & Bosworth, 2000).

The stages are outlined pictorially in Figure 6.



Stages of change model

Figure 6: Stages of Change Model (Kern, 2005)

#### Handy Hint!

Do not apply a one size fits all approach to interventions.  
Different approaches are required for the different stages of change.

## 4 Client Case Studies – WA

It is important to learn from others who have been part of an intervention. The following two case studies have been written by clients of *Health Partners*, the WA CDSM program, and explain what it has meant to them to be part of the program.

### 4.1 Esther

*I started to attend the Live Life Club following a car accident which caused me to lose my job. That in turn caused me to go into severe clinical depression. I received so much encouragement and support from the Live Life Club members and gradually I found another purpose in life.*

*Supported by the Canning Division of General Practice, a group of us from the Live Life Club commenced a walking group called the 'Healthy Heart Walkers'. This has grown well and the friendships made from attending both groups have been very important to me. My depression gradually lifted with medication and support from my friends.*

*I was then encouraged to attend a workshop called 'Living Life with Chronic Conditions'. The techniques I learnt here have been invaluable. The sessions on relaxation, making an action plan, communication skills, working with your health care professional etc have helped me so much.*

*I am now a facilitator of the Living Life with Chronic Conditions course and my aim is now to put back a smile on someone else's face and equip them with the skills to manage their health better.*

### 4.2 Stuart

*My name is Stuart – I enjoyed good health and an active life until 3 years ago I found out I needed to have bypass surgery and was operated on immediately. It all happened so fast it was bewildering – it wasn't until lying sleeplessly in my hospital bed the night before surgery that what was happening to me really registered and I became quite anxious about my condition.*

*When I was discharged from hospital I felt very vulnerable at being separated from all the professional care and equipment. I even asked my daughter who is a nurse to sleep over at my home for the first 2 nights. Although I was fortunate enough to have a loving wife to care for me, I really felt very insecure, vulnerable and exposed to a very uncertain future.*

*To help speed my recovery process I attended a seven week cardiac rehabilitation program run by the Canning Division of General Practice. At the conclusion of this program, I was asked if I wanted to attend a workshop called Living Life with a Chronic Condition. Although the cardiac program had helped me, I felt that I had only just started on the road to recovery and was determined to do all I could to regain as much health and strength as possible so I agreed to go to the workshop.*

*At the workshop I learnt to set goals, maintain an exercise schedule and to plan an appropriate diet. It also helped me to look beyond myself to the needs of others. Sharing my concerns with others and hearing that they were going through the same problems I was helped me a lot.*

*The workshop's constructive approach to the future helped me to feel more secure and confident. With a lot of support from my wife who also attended the workshop with me, I began to have a more positive outlook on life. When the workshop came to an end, my wife and I were told about a support group we could attend called the 'Live Life Club'.*

*I went along to the Live Life Club in an attempt to continue with my recovery. At the Club I found that most of the group were also limited by some major health challenge and we have all been a support to one another. Many of the guest speakers that come along to the Live Life Club have provided useful information regarding avenues of self help that are available to us. I now feel determined to continue managing my health needs and would rather die with my boots on than 'fizzle out' without having done all that I could to improve my health.*

## 5 Health Professional Training

Although the term 'self management' is readily used in some disciplines, the concept of 'chronic disease self management' is still relatively new. Many health professionals working with people with chronic diseases have been taught the traditional medical model of health care and are unfamiliar with CDSM. It is important, however, that health professionals receive CDSM training and incorporate these skills into daily practice. CDSM training allows health professionals to assess clients self management capacity and facilitate self management.

Comprehensive training programs to enhance self management have been developed and evaluated. In Australia, the two most common and successful CDSM training packages offered to health professionals are the Stanford and Flinders models. The Stanford and Flinders models are complimentary approaches to CDSM and it is recommended that any health or social service professionals working with a CDSM program be trained in both of these models.

The Stanford Model was developed by Kate Lorig and associates at Stanford University, USA. It enables people to work in a group setting, to understand the components of self management and to learn skills and strategies that will help to improve their ability to manage their lives (see Section 2.2.1). It uses peer educators and standardised structured sessions.

The Flinders Model was developed by Malcolm Battersby and associates at the Flinders Human Behaviour and Health Research Unit (FHB&HRU) in South Australia. The model is underpinned by cognitive behavioural therapy (CBT) principles and offers a generic approach to chronic condition self-management that can be applied to a wide range of health conditions. The training is most beneficial to the primary health care workforce who works one on one with clients. This model provides a structured, client centred framework for collaborative problem definition, goal setting, care planning and review.

As with the interventions outlined in Section 2, these training workshops are certainly not the only options available in CDSM. These two workshops are presented as the Canning Division's experience has shown them to work successfully and the evaluation of these workshops has proven that they meet the self management training needs of the health professionals in WA.

### 5.1 Chronic Disease Self Management Workshop (Stanford Model) – Group Training Workshops

The Stanford approach to CDSM, which is delivered in a group setting, has been outlined in Section 2.2.1. Health Professionals can be trained to lead these self management workshops for clients in a health or community setting. The processes required to implement this approach are outlined below.

#### 5.1.1 *Stanford CDSM client workshop leaders training*

The Stanford client workshops (see Section 2.2.1) are run by two leaders trained in this model. Organisations can opt to have both staff and consumers (someone who has a chronic condition) trained as leaders to run these workshops. A leaders training workshop is delivered over three full days, but may vary from organisation to organisation depending on how it is structured. The workshop is delivered by two Master Trainers.

#### 5.1.2 *Recruitment of Leaders*

If planning to include the Stanford CDSM client workshops as part of a CDSM program, it is necessary to put some thought into training staff members to deliver this workshop model. It may also be worthwhile to consider training any consumers or clients you think would be a good role model to participants in the workshop as co-facilitators.

New leaders need to be trained through an organisation licensed to deliver the Stanford Model training. For information on the nearest organisation licensed to deliver this training access the Stanford University website on <http://patienteducation.stanford.edu/organ/cdsites.html>

The main requirements for leaders is that they need to be able to read and speak well, to follow directions, be healthy enough to commit to teaching a six session workshop and to be enthusiastic about the course. Successful leaders range from being young to old, male or female, working or retired, health care professional to no medical experience. People who are focussed on their disease tend to not be good leaders. It is important for leaders to remember that their role is that of facilitator and not participant. Leaders who are absorbed with their own health issues may struggle with facilitating problem solving and discussing the issues of others.

In order to keep skills sharp and retain enthusiasm for the program, it is preferable that trained leaders facilitate at least two workshops a year. It is a good idea to ask new leaders to agree ahead of time to teach at least one workshop per year. Some organisations that run a large number of workshops ask leaders to sign a commitment to lead a greater number of workshops per year.

Sourcing community members to become trained as peer facilitators can be done in a number of ways. Asking community members involved in other programs run by your organisation to become a facilitator is one option. Another option is to observe clients who actually attend the workshop as part of the CDSM program for their suitability to become peer facilitators. Clients who demonstrate that they have firmly grasped the self management principles and possesses facilitation skills may be excellent candidates to become trained as leaders.

#### **WA Example**

*Health Partners asked for expressions of interest for leaders at the Live Life Club support group. Many of the good self managers were eager to be trained as leaders in the workshop and have been involved in leading the groups for over 3 years! Participants really identify with the leaders and see them as a powerful role model in the group.*

New leaders should ideally co-facilitate their first workshop with an experienced facilitator and should be offered support and encouragement. Feedback at the end of workshop sessions helps in reinforcing best practice as well as encouraging and supporting the leader. Peer feedback is the best form of feedback, whereby each leader shares feedback with the other leader.

### **5.1.3 Supporting Leaders**

Organisations running these workshops need to support and recognise the efforts of their community leaders. Make them feel valued and respected. Try to meet with them twice a year and provide them with a morning tea thanking them for their help. Together you can talk with each other about any issues that they may have such as their teaching skills, working with their co-leader, managing individuals in the group, resources, getting answers to questions, etc. They should be given a chance to share their 'stories' about their experiences. Make sure leaders know how to reach someone who can help them if issues arise.

### **5.1.4 Levels of Training in the Stanford CDSM Model**

Levels of training for the Stanford CDSM client workshop model include:

- **Workshop Leaders** – able to run client workshops. Leaders are trained by Master Trainers. In Australia there are various organisations which offer leaders training. Visit <http://clienteducation.stanford.edu/organ/cdsites.html#aus> for more information.
- **Master Trainers** – able to train participants to be leaders as well as run client workshops. There are some organisations within Australia who offer Leaders Training. Visit: <http://clienteducation.stanford.edu/organ/cdsites.html#aus> for a list of licensed organisations to contact in your region to enquire about Leaders Training.
- **T Trainer** – this is the highest level of training and can only be acquired through supervision from Stanford University. A T Trainer is able to train leaders, master trainers and run CDSM workshops.

It is necessary for anyone leading a CDSM workshop to have at least completed Leaders Training. To be effective in their roles, T trainers and Master trainers should continue to lead client workshops periodically as this will keep skills current and adds relevance to the higher levels of training being conducted by the Master Trainer or T Trainer.

### **5.1.5 Payment of Leaders**

Most organisations will provide some form of payment to community leaders. It is important to remember that community leaders may be leading a workshop alongside a salaried employee. The Community leader should not be made to feel less valued.

## **5.2 Flinders Chronic Disease Self Management Workshop – Individual Practitioners**

Flinders Human Behaviour and Health Research Unit (FHB&HRU) has developed a generic set of tools and processes that enables health professionals and clients to undertake a structured process to assess self management capacity in people with chronic conditions. It involves identifying self management behaviours, collaborative identification of problems and goal setting leading to the development of individualised care plans. The tools include the Partners in Health Scale, Cue and Response Interview and the Problem and Goals assessment.

The aim of the model is to provide a consistent, reproducible approach to assessing the key components of self management that:

- Improves the partnership between the client and health professional(s)
- Collaboratively identifies problems and therefore better interventions
- Is a motivational process for the client and leads to sustained behaviour change
- Allows measurement over time and tracks change
- Has a predictive ability, i.e. improvements in self-management behaviour as measured by the PIH scale, relate to improved health outcomes (Battersby, Pols, Markwick, Lawrence & Williams, 2005)

This is a clinician-led model, and is beneficial to those health professionals who work with clients on an individual basis whether it is by phone or in person.

### **5.2.1 Training Workshops**

The training workshops run over a period of two days. On completion of the workshop, participants will be able to:

- Understand the principles of chronic disease self management.
- Administer the Partners in Health Scale. This scale is completed by the patient, the results of which will identify those areas where they are managing well and those areas that need further support and action.
- Understand and administer a Cue and Response Interview. This is used in conjunction with the Partners in Health Scale and allows for further understanding of the patient's self management practices.
- Undertake a 'Problem and Goal' assessment. This allows problems to be clearly identified from the patient's perspective.
- Use a range of interventions and strategies for self management.
- Develop a Care Plan that includes the identified self management issues, the relevant interventions and strategies, and the problems and goals as identified by the patient.
- Understand the principles of 'Stages of Change'.
- Understand the concept of Motivational Interviewing and Structured Problem Solving.

### **5.3 Other Relevant Training or Professional Development for Workforce in CDSM related topics**

The training described so far in this manual is certainly not exhaustive. Some other ideas for professional development for people working with clients with chronic conditions include:

- Motivational interviewing
- Cultural sensitivity training
- Enhanced primary care training
- Disease specific education (eg. diabetes education)
- Anxiety management
- Recognition and treatment of depression
- Cognitive behavioural principles of step by step change

It is a good idea to conduct a training needs assessment at the end of each professional development session. This will give an idea of what education the trainees are requiring to upskill in their field.

## 6 Evaluation

Evaluation is an important part of running a CDSM program, or any program for that matter. Program evaluation offers a way to understand and improve community health and development using methods that are useful, feasible, proper and accurate.

Evaluation processes should be identified and put in place from the beginning of a program's development stage. It's important to continually engage in the process of asking questions, reflecting on the answers to these questions and reviewing ongoing strategies and actions. This process will promote continual program development by providing feedback about the program's progress, encouraging reflection on outcomes and providing a basis from which to consider future strategies (Commonwealth, 2001).

Remember to be flexible and don't feel negative about having to change or modify components of the program if they are not working. Being able to recognise that something isn't working and making the steps to rectify the problem is an essential element for the success of any CDSM program.

**Handy Hint!**

Ongoing evaluation is essential to know what is working, what isn't working and what needs to be changed.

## 7 CDSM Case Study Examples

The following case studies demonstrate how a health professional can take a client with a chronic condition through a structured process to identify a range of self management issues in their life. These case studies show how a client and their health professional are able to work in partnership to explore these issues further, leading to collaborative strategies and interventions that will encourage behaviour change and improve self management skills.

The case studies follow the Flinders Chronic Condition Self Management Model for this process (see Section 5.2 of the manual for more information) and there is particular reference to the three assessment tools throughout this section. These are:

- ***The Partners in Health Scale (PIH)***

This consists of 13 questions that reflect the principles of self management and is completed to get the clients perspective of their own self management. This is a self assessment and the client rates their answers on a 9 point scale ranging from 0 = very good to 8 = very poor. The scale can be completed prior to the client seeing the health professional (i.e. via post, in the waiting room, via phone).

- ***The Cue and Response Interview***

The Cue and Response interview is an extension of the Partners in Health Scale and provides the health professional with an opportunity to gain a greater insight into their client's current self management practices. The interview enables the collaborative identification of issues together with the client, leading to discussion of what specific areas the client is ready to improve on and with what particular interventions.

- ***Problems and Goals Assessment***

This tool is used to work with the client to identify what they see as their main problem, what happens to them because of the problem, and how this makes them feel. The client is then encouraged to set a goal that, if achieved, would reflect some change in that particular problem or its impact. Both the client and health worker can score the problem and the goal on a 9 point scale.

- ***Care Plan***

The care plan is used to record the issues identified from the Cue and Response Interview and the Problems and Goals Assessment. It also contains all the strategies and interventions that may help to address the identified issues which have been discussed and agreed on.

### Case Study 1

#### Background

Pamela is a 57 year old lady who is married with two children, one of whom still lives at home and is financially dependent on his parents. Pamela had to give up her job recently as an administration officer due to continuous ill health. Her family tends to live their own lives and don't particularly concern themselves over Pamela's health conditions. They have recently moved house into a different suburb causing considerable stress to Pamela.

Pamela has a good, trusting relationship with her GP who has, as a whole of practice approach, begun making sure that all of his patients with long term chronic conditions are managed with a care plan. This involves an initial assessment by the practice nurse.

Pamela has emphysema and asthma, with two, week long hospital stays in the past three years due to pneumonia. She also has irritable bowel syndrome which causes cramps and bloating. Two years ago she was diagnosed with rheumatoid arthritis which has had a large impact on her physical activity levels. The main issues in the last year for Pamela have been pain, decreased ability and frustration. She feels unable to talk to family/friends about her poor health.

She complains of feeling totally down and out due to the constant pain she is in. She can't do anything that she used to do.

In the past all of Pamela's health professionals have treated her symptoms and tried to educate and help her, but nothing seems to have improved how she manages her health problems.

### **Self Management Assessment**

Using the Flinders self management tools, the practice nurse looks into more detail about how Pamela is managing her health. These tools allowed them to work in partnership to come up with strategies and interventions which may be useful to Pamela in managing her condition and the impact it is having on her life.

### **The Partners in Health Scale and the Cue and Response Interview**

In assessing her own self management capacity, Pamela thought she was self managing well. She knew what the causes of her conditions were and understood what treatment options she had. Pamela also told the nurse that she was currently on anti depressants. She had a good relationship with her family but she did not have much support from them. This was mainly due to the fact that she had not told them about her illness, rather keeping it to herself, and causing herself stress.

Pamela was taking her medications correctly and knew that her conditions, particularly the arthritis, would be considerable worse if she did not take them. She spoke of not really knowing what each pill was for, as there were so many different tablets.

Pamela was comfortable with her GP and felt involved in decision making. She attended all appointments with other health professionals.

Both the practice nurse and Pamela agreed that she was not self managing well in a few areas particularly related to symptom management. She tended to only visit the GP when she felt unwell, rather than monitoring or measuring particular symptoms as they arise. She knew that stress made the IBS symptoms flare up.

There was also agreement that Pamela was not managing the impact that her conditions had on her physical activity and the emotions and social aspects of life. She felt quite alone and didn't have anyone to talk to about the struggles she was facing with her illness.

She tended to live a healthy life, felt that she ate nutritiously and had quit smoking about 6 years ago. She wasn't as physically active as she would have liked to be, the pain preventing her from exercising.

### **Self Management Issues**

During the interview, Pamela and the practice nurse discovered a number of issues that were affecting her ability to self manage well.

1. Pamela knew what her symptoms were but didn't realise that she should measure and record them regularly.
2. Pamela didn't know how to measure and record these symptoms so was keen to find a tool to record this information.
3. Pamela wasn't able to do much exercise due to the IBS and the pain of the arthritis.
4. There was no support from family, as they did not know about her conditions, leading to Pamela having to do more around the house.
5. Pamela felt lonely and had no one to talk to about the way she was feeling.

6. Pamela was a bit confused as to what medication she was on, although she was following the instructions of her GP.
7. There seemed to be frequent stressful episodes in Pamela's life, which lead to her physical symptoms flaring up.

### Problems and Goals Assessment

The nurse undertook a Problems and Goals Assessment with Pamela and she identified her main problem as:

"Pain affects everything I do mentally and physically, stopping me from doing my normal, everyday activities which make me feel pretty down and out."

Pamela also set a goal:

"To go to the shops on Wednesdays in the morning for a brief look around for one hour."

### Care Plan

At the care planning session Pamela agreed:

1. To ask her GP about:
  - a. A symptom monitoring diary to record her signs and symptoms
  - b. An action plan for symptom changes
  - c. A pulmonary rehabilitation program
2. Talk with her husband about her conditions, then eventually leading to a whole family discussion about what she is going through.
3. Discuss with pharmacist the best options for pain management.
4. Discuss with GP the possibility of having a Home Medications Review.
5. Explore alternative options such as massage, hydrotherapy etc.
6. Enrol in a generic self management workshop which would give her information about managing the impact her condition has on her life. It would also give her an opportunity to speak with others with similar conditions.

### Progress

Pamela was seen a fortnight later with her husband. She had sat down with him and explained that she had been suffering and what she needed from him and their family in terms of support. Her husband was supportive and they agreed to have a family discussion in a fortnight, once one of their children returned home from overseas. Even this small step of speaking with her husband had alleviated some of her stress.

Her GP had given her a symptom monitoring diary on her visit and had helped her source a generic self management program running in her area, but this was going to be starting in a month. The GP also referred her for a HMR and the pharmacist was due to visit with her at the end of that week.

Pamela was reviewed regularly every 6 weeks. After 3 months, she was able to regularly complete her goal of going to the shops for a walk around, and was ready to set another goal which was to source a local hydrotherapy pool so she could start exercising there. She was feeling much more confident about going out and did not feel as stressed. She had talked with her family and they were more supportive of her and were actually doing some chores around the house. Pamela attended a 6 week Chronic Disease Self Management workshop and found it to be extremely helpful, giving her some techniques to try to relax and new skills in monitoring the signs and symptoms of her illness. She also had a new 'buddy' from the workshop who she 'clicked' with as they both found they had some of the same conditions. They are currently meeting every fortnight for a cup of tea.

At a six month review Pamela was attending hydrotherapy once a week and she reported that she was feeling less pain, although not completely pain free. She was keen to keep continuing at the pool as she could definitely 'feel the difference'. Pamela also reported feeling happier, and finding that even as a family they seem to be more open now about things.

Pamela was now monitoring her symptoms daily and decided with the practice nurse that perhaps she should go and visit a dietician to discuss what dietary changes she may need to make to prevent the IBS symptoms flaring again. She was still visiting with her friend from the workshop and they had decided together that they would join a support group so they could meet with others who shared the same experiences.

Pamela will return for review in another two months.

## Case Study 2

### Background

David is a 66 year old, divorced man who lives alone. He has older children but they live in the eastern states so he rarely sees them. He retired from his job about 4 years ago where he repaired concrete in his own small business.

David was diagnosed with type 2 diabetes nine years ago and has been prescribed tablets to control it. He is very overweight, has high cholesterol and does not exercise at all and tends to eat mostly take-away or pre-prepared meals from his local 24 hour shop.

David has not seen the point in taking care of his body in the past and has lived a somewhat carefree life, not thinking of the consequences and only stopping bad habits when they make him feel unwell. He has in the past been a smoker and heavy drinker, but stopped both of these habits over 10 years ago as he was not feeling healthy. He complains of tiredness and feeling lonely.

He is now been referred to a chronic disease team by his GP who thought he would benefit from such a program.

### Self Management Assessment

Using the Flinders self management tools, the practice nurse looks into more detail about how David was managing his health. These tools allowed them to work in partnership to come up with strategies and interventions which may be useful to David in managing his condition and the impact it is having on his life.

### The Partners in Health Scale and Cue and Response Interview

David felt that he was a very good self manager of his condition. The nurse agreed in many ways but there were also some areas where he needed some assistance.

David had a good knowledge of his condition and always did what his GP recommended, including taking his medication correctly. He had recently started taking some 'natural' medicines from a health food store but had not informed his pharmacist or his doctor. He says that he has some side effects from the medication which affects his bowel movements and complains of being very fatigued.

David has a satisfactory relationship with his GP. He only talks with him about medical related matters. He does as he is told and seems to think he shares in decisions. He always makes appointments and attends them. He says that his GP constantly tells him that he should lose weight, but David does not know where to start.

David does not regularly monitor his blood glucose levels, and does not know how to manage symptoms if they get worse.

David is coping with back pain as well at present (for the last few months) and is currently finding the physical pain to be very limiting and he is unable to do some of the things he enjoys doing.

He appears to be depressed and stressed by his condition but does not see it as a barrier to his social life. However, when questioned further about his social life by the nurse, it seems he doesn't go out much, preferring to stay at home and watch TV. He says that he can't get out much at present because of the back pain. He says that it would be nice to get out and about though.

He is not exercising at all and his diet is extremely poor.

### Self Management Issues

During the interview, David and the clinical nurse specialist discovered a number of issues that were affecting his ability to self manage well:

1. David is taking some 'natural' medicines that need to be discussed with his pharmacist or GP.
2. David seems to be experiencing some side effects from his medication that need to be discussed with his GP.
3. David feels fatigued a lot of the time, particularly towards the end of the day.
4. David not measuring or recording his symptoms.
5. His back pain is physically limiting and he is not getting out of the house at all, preferring to lounge around in front of the TV.
6. Feeling low and depressed has been common for the last couple of months.
7. David did feel lonely as a result of being housebound with the back pain.
8. David diet consists of mainly takeaway foods.
9. David was concerned about his weight, but finds it too overwhelming.

David understood that he could be exercising more but currently feels unable to do so, because of the constant pain in his back.

### Problems and Goals Assessment

The nurse undertook a Problems and Goals Assessment with David and he identified his main problem as:

"The pain in my back means I can't do anything but lie around making me feel lonely and depressed."

David rated this problem is quite severe.

David also set a goal with the nurse:

"To walk around the garden in the sunshine every afternoon for 10 minutes."

### Care Plan

At the care planning session David agreed:

1. To ask his GP about:
  - a. A symptom monitoring diary to record his signs and symptoms
  - b. The natural medicines he has started taking
  - c. The possible side effects of his medication
  - d. The fatigue he is feeling
2. To visit a physiotherapist regarding his back pain.
3. To ring Diabetes Australia about possible workshops to enrol in to learn more about symptom and signs he should be monitoring.
4. To make an appointment with a dietician to discuss nutrition options for people with type 2 diabetes.
5. To get out of the house a bit more in the sunshine to see if this increases his mood.
6. To visit with his elderly neighbour once a week to alleviate his loneliness.

## Progress

David was seen three weeks later. In this time he had visited with his GP and discussed the possible side effects of his medication. His GP adjusted his medication and David felt that he was feeling a little better, but was still having problems with his bowel movements. Both the nurse and David made an appointment with a dietician for the following week to see if his diet was possibly causing his bowel problems and constant tiredness. He had expressed that his diet consisted of mainly highly fatty foods, which seemed likely to be causing the problems.

His GP had given him a symptom monitoring diary and David has contacted Diabetes Australia and has enrolled in a Living with Diabetes Workshop. He has visited a physiotherapist and is having weekly visits at the moment, as well as being given some stretching exercises to do daily to help alleviate his back pain. Although the physiotherapist visit was last week, David has not started the exercises as yet. He was, however, able to achieve his goal of walking in the garden for 10 minutes quite easily and he gradually increased this each week.

David was reviewed again at eight weeks. Over this period of time he had successfully completed education on Diabetes which then led to the completion of a generic self management workshop. He joined a support group at Diabetes Australia which allowed him to meet with people regularly who lived with the same condition.

After the second visit with the physiotherapist he began his exercises for his back, albeit slowly at first. Once he got going he started feeling a bit better and his back pain started to lessen. After 3 months, he had started going out for a walk to the park and was finding that he was feeling happier as he no longer was cooped up at home. He had also implemented some dietary changes after visiting the dietician. He couldn't quite manage to cook for himself yet, but had learnt to substitute some of his takeaway foods for lower fat takeaway options. His fatigue started to lessen after these dietary changes and he was feeling a lot brighter from his social outings.

David will return for review in another two months.

## Case Study 3

### Background

Douglas is a 69 year old man with cardio myopathy and emphysema. He has been married for 45 years and his wife has a heart condition and is often unwell. They recently shifted from their larger home into a smaller, more manageable retirement villa. He retired from his job about five years ago and predominantly spends his time caring for his wife. They don't have any children.

Douglas manages at home quite well but is often short of breath and feels quite unfit in being able to go for walks like he used to. He believes that he has neglected his fitness and is realising that his smoking is making him worse.

He is looked after by his GP and a heart specialist. He is now been referred to a chronic disease team by his GP who thought he would benefit from such a program.

### Self Management Assessment

Using the Flinders self management tools, the practice nurse looks into more detail about how Douglas was managing his health. These tools allowed them to work in partnership to come up with strategies and interventions which may be useful to Douglas in managing his condition and the impact it is having on his life.

### **The Partners in Health Scale and Cue and Response Interview**

Douglas reports that he has a very high knowledge of his condition and his treatment, however, upon being assessed, the nurse in the chronic disease team, considers his knowledge to be quite low. He is compliant with his medication, but doesn't know what each is for. He takes one particular medication extra if he gets out of breath. He takes his puffers with him wherever he goes. If symptoms don't settle he goes to the doctor.

When asked about his smoking he agreed that he should give up and will with help.

He says he has a good rapport with his specialist and also his GP. His usual GP retired a year ago and so he is still getting to know his new GP. He always arranges and attends appointments.

He does measure his weight and shortness of breath in a monitoring diary given to him by his new GP. He often feels fatigued.

If he gets short of breath he rests and only goes to the doctor if he is very sick. In regards to managing the impact the condition has on his physical activity he says that he cannot walk far and cannot go up an incline.

In discussing the emotional social aspects of his life, he says that he is much happier since he has moved to his new place however still feels a bit lonely, as his wife sleeps a lot. He feels life is pretty good at the moment but isn't as social as he would like to be. Douglas doesn't get out much because his wife is unwell most of the time and doesn't feel like going out.

He tries to eat the right food, what he thinks is low in fat and low in sugar. Says that he and his wife prefer to eat plain English food, and they are not into 'fancy' pastas and Asian foods.

Douglas spoke about wanting to give up smoking and this is something he still wants to achieve.

### **Self Management Issues**

During the interview, Douglas and the nurse discovered a number of issues that were affecting his ability to self manage well:

1. Lack of knowledge of his condition, particularly the heart condition.
2. Douglas did not know much about the treatment he was on.
3. Douglas is still smoking up to 10 cigarettes a day, but is willing to do something about this with help.
4. Social isolation – Douglas doesn't seem to get out of the house as much as he used to.
5. Douglas seems to be spending a lot of time caring for his wife, which is quite hard work.
6. Douglas is feeling fatigued quite a lot.
7. Medications are quite confusing to Douglas and he seems to be taking them when his signs and symptoms flare up rather than on an ongoing basis.
8. Douglas wants to go out walking and exercise more but his short of breath prevents him doing so.
9. He experiences swelling and puffiness occasionally.
10. Douglas needs to maintain an optimum nutritional status.

### **Problems and Goals Assessment**

The nurse undertook a Problems and Goals Assessment with Douglas and he identified his main problem as:

“The fact that I get short of breath walking up hills prevents me from going to the club to see my friends and makes me feel lonely and somewhat isolated from the outside world.”

Douglas rated this problem as interfering with his daily activities quite often.

Douglas (reluctantly at first) set a goal with the nurse:

“To organise a taxi to get myself to the club on Thursday mornings each week.”

## Care Plan

At the care planning session Douglas agreed:

1. To contact the Heart Foundation about learning more about his condition and treatment and perhaps linking in with a support group with people with similar conditions.
2. At the next appointment with his cardiologist, to ask for some information sheets so he can learn more about his treatment.
3. To ring QUIT line to talk with someone about quitting smoking.
4. To organise with neighbour to meet more regularly for a cup of tea and a chat.
5. To contact HACC about getting some home help and care for his wife.
6. To talk to his GP about:
  - a. Getting a Home Medicines Review (HMR).
  - b. Enrolling in a cardiac rehabilitation program (which will help shortness of breath).
7. To contact a dietician to discuss his healthy food options.
8. To discuss with a social worker how to obtain half price taxi vouchers so he can go out more.
9. To enrol in a generic chronic disease self management workshop which will give him the tools to manage his condition.

## Progress

Douglas was followed up a fortnight later. He has visited with his GP in this time and had been referred for a HMR and his GP had sourced a cardiac rehabilitation program through the local Division of General Practice. He was going to be starting this in the next month. Douglas had also contacted the Heart Foundation himself, and was put in contact with a heart support group which he was keen to meet up with, although he had not at this stage, pursued this any further. He had also found out himself about the half price taxi vouchers he was eligible for, but had not ventured to the club yet. He was still waiting to find out about the help he could possibly get for his wife, before he felt alright to go out of the house without her. The nurse praised Douglas on his progress so far and talked to him about what some of his next short term goals were.

Douglas visited again with the nurse a fortnight later. In this time he had found that he and his wife were eligible for some home help, through HACC, which was going to be starting in a week or so. He felt relieved to know that some help was going to be on its way. He had also been spending a little more time with his neighbour and they had started playing chess together. Some of his medication had also been adjusted in this time as a result of the HMR.

Douglas and his wife had visited with a dietician and found that some of the food they were eating, albeit quite plain, was actually quite high in salt and fat, so they learned some changes they could make to their meals to rectify this.

Douglas was reviewed again after a month. In this time he had started the cardiac rehabilitation program and was feeling quite good about himself. He also had met some great people who had some of the same symptoms as him in the past.

Over time, Douglas completed the cardiac rehab program, which also gave him the opportunity to further enrol in a self management workshop. In this workshop he learnt some new techniques for relaxation which he had never thought about before. He had implemented some of these techniques at home, such as deep breathing, and was finding it quite useful. He had started to go to the club on the days where his wife was feeling quite well – he had even purchased a mobile phone, so that his wife could ring him if she needed him home earlier (this was a suggestion from another participant in the self management workshop).

Douglas was feeling less lonely and more positive about the future. Not only was he feeling healthier and less fatigued, but his life felt fuller. He felt confident that he could now try to stop smoking. He was ready to ring QUIT line and was planning to once he got home.

Douglas will be reviewed every three months.

## Case Study 4

### Background

Karen is a 50 year old lady who has recently been diagnosed with COPD. She is very anxious about the future and afraid of not being able to breathe. Her husband and three children are very supportive of her (even to the point of fussing). She has had an active life up to now, and usually spends weekends away with her family. She is an ex-smoker.

Karen has had to have time off work and is happy that her work has been very accommodating about this, allowing her as much time as she needs.

She is managed by her GP at present. Karen's GP has started to have all his patients diagnosed with a chronic condition assessed for self management capacity in order for a care plan to be developed. All patients recently diagnosed will be given a patient hand held record to keep and take with them to all their appointments. The initial assessment is with the practice nurse and thereafter with the GP who works with her through her care plan.

### Self Management Assessment

Using the Flinders self management tools, the practice nurse looks into more detail about how Karen was managing her health. These tools allowed them to work in partnership to come up with strategies and interventions which may be useful to Karen in managing her condition and the impact it is having on her life.

### The Partners in Health Scale and the Cue and Response Interview

The self management assessments showed that Karen does not have much knowledge of her condition. She had only been recently diagnosed and was still in shock. She had not received much information as yet and was feeling out of control. Her family and friends were supportive but were fussing over her.

Karen's knowledge of treatment was quite limited. She did not have any inhalers as yet although her GP has mentioned 'Spiriva' to her. She was not aware of any other treatments for COPD. At present the only medication she has been taking was hormone replacement therapy.

When talking about her care, Karen said that she had a relatively new GP and feels that he is very understanding and caring. When she is in the consultation room she says that she tends to forget things and remembers them in the car on the way home. She has no trouble arranging and attending appointments with the GP or other health professionals.

Karen understands that she should be recording any changes in her sputum production but is not recording them at present. Everything feels so new at the moment and she feels she needs to get into a 'new routine' to manage this. She doesn't really know how to manage her symptoms at the moment, and only knows that she should just go the doctor when things get too bad and she can get some antibiotics.

The illness seems to be already having an impact on Karen's physical activity. She used to enjoy going away for weekends with her family and a few other families. She thinks that perhaps she won't be able to do this as she will be a burden to everyone. She is still able to work but can't do much exercise as she gets too puffed – which is another reason why she doesn't think she should go on holidays anymore. She does, however, still walk her dog daily.

As this is a new diagnosis, everything has come as a shock. Karen is feeling very tearful at the moment and is scared for her future. She is willing to do anything to stay healthy for her family.

Karen was a smoker but quit six months ago 'cold turkey' as she found she was coughing a lot. This has helped ease the coughing.

## Self Management Issues

During the interview, Karen and the practice nurse discovered a number of issues that were affecting her ability to self manage well. These were:

1. Being recently diagnosed, Karen does not have very much knowledge of COPD.
2. Karen does not have much knowledge of the treatment available.
3. She is feeling very anxious about the future.
4. Her family is fussing over her.
5. Karen forgets some of the things she wants to talk to her GP about.
6. Karen needs to be aware of what symptoms she should be monitoring and also how to do this.
7. Karen feels she is unable to go on holidays anymore for fear of being a burden.

## Problems and Goals Assessment

The practice nurse undertook a Problems and Goals Assessment with Karen and she identified her main problem as:

“Feeling breathless prevents me from enjoying activities with my children which makes me feel really unhappy.”

Karen also set a goal with the nurse, which was specific and doable for her at the moment:

“To take my three children out for dinner next week and spend some quality time with them without over exerting myself physically.”

## Care Plan

At the care planning session Karen agreed:

1. To ask her GP about taking part in a COPD program which will increase her knowledge and skills for manage her condition.
2. To enrol in a generic chronic disease self management workshop which will give her skills to manage the impact the COPD may have on her life.
3. To talk with her family about their fussing.
4. To keep a list of all the things she wants to talk to her GP about, and make sure she takes it with her to every appointment.
5. To talk with her husband about how she still wants to go away but how they could perhaps change where they are going to a less physically active place.

## Progress

Karen met with the nurse a month later. In this time she had completed her goal of taking her children out for dinner and had an enjoyable time. She had realised that she still could do some activities with her children without over exerting herself. She was keen to readjust the goal with nurse and actually spend some time taking her youngest child shopping.

Karen had visited with her GP and expressed her concern about her lack of knowledge and that she was keen to find a COPD program that she could take part in. She had written a list to take with her so she did not forget all the questions and queries she had. She was referred to a program through the local Division of General Practice and was due to visit with the program the following week.

After another month, Karen felt that she was more in control of her condition and knew what signs and symptoms she should be monitoring regularly. She also began to understand what her limitations were. She had also begun a chronic disease self management workshop where she was learning new problem solving skills. She realises that if she can't do something, she will try something more manageable, but equally fulfilling. This is making her feel more positive about the future.

Over time, Karen became less overwhelmed by her condition. By attending the COPD program she learnt that there were some exercises that she could do to increase her fitness, which made her more positive. She had talked with her husband about some new adventures that they could go on.

Karen was also still able to spend time with her family and go to interesting places. She felt more confident in herself and was not seeing her condition as debilitating. Her family started to recognise this and stopped fussing as much over her.

Karen will be reviewed by the practice nurse every three months.

## Case Study 5

### Background

Carmel is a 53 year old business woman with type 2 diabetes. She has a family history of diabetes with her mother and grandmother also having the condition. Carmel travels interstate a lot for work and has a very busy routine. She has been divorced for three years and one of her two children is still living at home. She doesn't smoke but says she has a couple of wines each night with dinner to 'wind down'.

Carmel seems to be living a highly stressful working life and has little time for relaxation.

She is managed by her GP at present, who is managing all her patients with care plans. This means that Carmel needs to be assessed. The GP hires a practice nurse from her local division to undertake these care plan assessments, so she doesn't burden her already overworked practice nurses. The practice then takes over the management of the patient thereafter.

### Self Management Assessment

Using the Flinders self management tools, the practice nurse looks into more detail about how Carmel is managing her health. These tools allowed them to work in partnership to come up with strategies and interventions which may be useful to Carmel in managing her condition and the impact it is having on her life.

### The Partners in Health Scale and the Cue and Response Interview

The self management assessments showed that Carmel has a reasonable knowledge of her condition, stating that diabetes can be serious if not under control. She was aware that she 'could go blind, have a stroke or have her foot amputated' if she didn't manage it well.

The knowledge of her treatment was again, fairly reasonable, but could be better. She only knew that she could take medication and was not aware of anything else (i.e. food or exercise). She takes Diaformin daily to bring down her sugars but sometimes forgets if she is too busy. She has flown out of Perth for work a number of times without remembering to take her medication.

Carmel was happy with her GP and is comfortable telling her anything. She was aware of the need to check her BGLs to make sure her sugars were low – however forgets a lot of the time due to other 'things' on her mind. If her BGLs are high (over 7) she stops eating sweets and fat.

Carmel says that she is far too busy to exercise and says that the condition is not having an impact on her physical activity. She says she has a million things to do everyday and exercise is not on the list. She does feel tired a lot, particularly lately.

Socially, Carmel gets out and about often, however, it is mainly to do with her business. She does spend time with her children, however they are in their 20s and spend most of their free time with friends. She says she has a close knit group of friends with whom she lunches monthly.

Carmel feels that she is living a healthy lifestyle but reports that she eats mostly 'Lean Cuisines' and pre-prepared frozen meals due to her not having the time to cook herself. She doesn't seem to eat much fresh food. She has a couple of glasses of wine with her dinner each night which helps her unwind. Her life seems to be highly stressful and although she doesn't acknowledge it, the practice nurse gets the feeling during the interview that Carmel is stressed and wanting to find time to relax.

## Self Management Issues

During the interview, Carmel and the practice nurse discovered a number of issues that were affecting her ability to self manage well. These were:

1. Only having a reasonable knowledge of her condition.
2. Only having a reasonable knowledge of her treatment.
3. Carmel sometimes forgetting her medication.
4. Lack of exercise.
5. Carmel feeling fatigued a lot of the time, particularly lately.
6. Carmel is not eating a nutritious diet.
7. She is living a highly stressful life.
8. Alcohol.

## Problems and Goals Assessment

The practice nurse undertook a Problems and Goals Assessment with Carmel and she identified her main problem as:

“I don’t have time to prepare dinner which makes me eat unhealthy foods which makes me feel bad and lazy.”

Carmel also set a goal with the nurse, which was specific and doable for her at the moment:

“To make an appointment with a dietician on my next day off (which is in a fortnight) so I can learn some new recipes for someone with type 2 diabetes.”

## Care Plan

At the care planning session Carmel agreed:

1. To get more information from her GP about type 2 diabetes and possibly treatments.
2. To enter a daily reminder message on her mobile phone of the need for her to take her medications.
3. To begin going for 30 minute walks on the weekends.
4. To talk to her GP about her fatigue.
5. Book an appointment with a dietician to discuss healthy meal planning specifically for people with type 2 diabetes.

Carmel acknowledged that her work life was overly busy and that she needed to start slowing down a bit to alleviate her stress levels, however, she felt that this was not possible to do at this time. She was happy to re-visit the idea again in a month when a particular deadline had passed.

## Progress

Carmel met with the GP a month later. In this time she had visited a dietician and learned some healthy meal options which she immediately began trying out. She realised that some of the healthy salads were as easy to prepare as the frozen dinners she was used to. Much to her dismay, she found that she had to cut down on her wine with meals.

She spoke to the GP about her need to learn more about her condition and her treatment options. Her GP suggested she visit with a diabetes educator who would be able to give her more information. Carmel agreed to make an appointment. She also spoke with her GP about her fatigue. The GP was confident that some of the changes written on her care plan, namely reducing stress, dietary changes and increasing physical activity, may help with the tiredness. The GP was keen to review this at the next appointment, once Carmel had a chance to incorporate all these new changes into her routine.

At the next follow up appointment, Carmel reported that she had begun an exercise routine of walking daily, whether that be for 30 minutes around her neighbourhood or walking around the airport when she was waiting for a plane. She was continuing to choose healthy foods and was finding that her tiredness had lessened.

Over time, Carmel acknowledged that her job was becoming too stressful and she allowed herself some more free time. She was able to keep her weekends free completely and made sure she limited her interstate travel to just once a month. This allowed her to keep to her new routines of exercise and diet. She had also started to enquire about joining yoga, to help relax. She was measuring her BGLs daily and was finding them to be very stable, further suggesting to her that she was on the right track.

Carmel will be reviewed by her GP every three months.

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