



Chronic
Illness
Alliance

**Helping people on the Mornington Peninsula
manage their chronic health conditions effectively**

An in-depth exploration of consumer needs for effective disease
management in the catchment area of Peninsula Health.

Report to Peninsula Health

EXECUTIVE SUMMARY

1. In August and September 2008 focus groups were conducted on behalf of Peninsula Health with people with COPD, diabetes and depression/anxiety. The aim was to explore local pathways to navigate the system from one service to another; the understanding by consumers of self-management approaches; consumers' experience of self-management, care planning and care coordination.
2. Seven focus groups were run by the Chronic Illness Alliance across the Peninsula Health catchment area.
3. A small survey was undertaken following the focus groups so that people who were not able to participate in the focus groups could also contribute.
4. COPD focus groups showed that people with COPD had concerns with
 - emergency services, emergency service personnel and information about what to do in an emergency;
 - information about all services;
 - safe use of oxygen and its supply;
 - support groups
 - exercise groups;
 - better informed health professionals and
 - transport.

Diabetes focus groups showed that people with diabetes had concerns with

- information about all services;
- integrated services;
- support groups as part of a more integrated service;
- centrality of the DNE;
- problems of flexibility for younger people with T1D;
- transport.

Depression/anxiety focus groups showed that people with depression/anxiety had concerns with

- information about all services;
- support services and support groups;
- integrated services in area for people with depression/anxiety inc outreach service;
- graded services;
- better informed health professionals/community;
- better services in public hospital for depression/anxiety;
- transport.

5. COPD groups had little understanding of self-management, poor access to information and a high reliance on emergency services; diabetes groups showed good understanding of self-management and had varieties of access to information and other services; people with depression and anxiety looked for empathic support services and personnel. They did not have developed understanding or experience of self-management. All focus group participants place a high value on support groups.
6. Based on these results we recommend
 - self-management programs in COPD and depression and anxiety;
 - developing models of information provision;
 - integrating support groups into care;
 - better communication;
 - greater use of care plans;
 - continuing education of health professionals on the needs of all people with chronic conditions and
 - building on the high value placed on specialist nurses by people with chronic conditions.

1. BACKGROUND

The Chronic Illness Alliance conducted an in-depth exploration of the needs of people living in the Peninsula Health catchment who have chronic obstructive pulmonary disease (COPD), all forms of diabetes and depression and anxiety. The aim of this exploration is to identify what consumers consider are the bases for the effective management of their conditions.

Focus groups provided the opportunity to explore a number of key issues including:

- Local examples of pathways for consumers of Peninsula Health services to navigate from one service to another;
- Consumer and carer understanding of the principles of self-management , care coordination, comprehensive assessments and care planning;
- Experiences of self-management interventions;
- Experiences of both primary and acute care services.

Following the focus groups a survey questionnaire was designed in consultation with staff of Peninsula Health. Surveys were distributed to interested people with COPD, diabetes and depression/anxiety. This distribution and the return of responses were undertaken by Peninsula Health staff to ensure confidentiality was maintained. The results and tables from each of the surveys appear in the Appendices, and are discussed in Section Four.

2. FOCUS GROUP COMPOSITION AND METHODOLOGY

There were seven focus groups conducted in August and September 2008. This number allowed Peninsula Health to explore the three conditions of COPD, diabetes and depression/anxiety separately at different geographic locations in the Peninsula, so as to take into account differences between the localities and circumstances of the consumers' lives. A focus group combining all three conditions was held at Hastings to include this demographic of consumers.

Recruitment was undertaken by staff from Peninsula Health in order to retain privacy. Recruitment included personal contact by staff; notices in the health services and contact with support groups and key individuals in the community.

Numbers in focus groups

In all, 39 people attended across all seven groups. These numbers were not evenly distributed across the groups, ranging from nine in one group, six in several groups and only two in another group.

Age represented in focus groups

Ages ranged from late 20s to people in their 80s. The younger people were two women with Type 1 Diabetes, a young man and young woman with depression. A parent who was the carer of an 18 year old son with type 1 diabetes was also present. While the age range was broad, most people were in the over 60s age group.

Gender in focus groups

As is usual with almost any health service consultation more women than men participated. However of the 39 participants, 16 were men. Two of the participants were women who were caring for men. The number of men attending was high by comparison with focus groups in other areas.

The focus groups were facilitated by Christine Walker with questions drafted in cooperation with Peninsula Health staff. The questions were designed to stimulate discussion among the participants of each group of their experiences of the range of services on the Peninsula, their views on the quality of services including their coordination, as well as their views on the gaps in services and how this might be addressed. In these focus groups, discussion of health services included those provided by Peninsula Health, primary care providers, private specialists and local government. Participants were paid a small honorarium to cover time and any incidental costs involved in attending the focus groups.

Table 1: Focus group composition

Condition	Location	Numbers of attendees
COPD	Rosebud	9 (4 men)
Diabetes	Rosebud	5 (1 man)
Depression/anxiety	Rosebud	4 (1 man)
COPD	Mt Eliza	6 (2 men)
Diabetes	Mt Eliza	7 (4 men)
Depression/anxiety	Mt Eliza	6 (2 men)
Three conditions combined	Hastings	2 (2 men)
TOTAL		39

Focus groups were recorded with a digital recorder and manually by a scribe to ensure all responses were recorded. Recordings were then transcribed and analysed thematically using the questions as the guide to the themes.

3. ANALYSIS OF EACH FOCUS GROUP

Rosebud COPD Group.

This group had nine participants, four of whom were men. All of the participants were in an older age group. Most were members of the 'Better Breathers' support group in Rosebud. One of the participants, a carer of her husband with COPD was the convenor of 'Better Breathers'.

Participants in this focus group largely saw their GPs for medical care. Some also regularly saw a physiotherapist. Only a small number mentioned they regularly saw a lung specialist. Most had spent some time in hospital for the care of their COPD. Participants spoke of hospital visits in the past. Most were on oxygen, though not everyone required it continually.

Experience of hospital discharge was variable across the group. Some participants had received good information from the hospital which had helped them manage at home. They gave examples where receiving instructions to manage their medication and receiving information on home help had assisted them manage at home. Others commented that their GP had not received any information about their hospital stay. One person felt the GP had been far better in assisting with clearing up an infection following hospital discharge than had the hospital. A participant remarked that he was discharged home with no information or help but had managed, though he knew another woman who had gone into complex care following a similar discharge experience.

While information on discharge was not always volunteered, all participants considered that obtaining information was difficult at any point in their care. Ward nurses and respiratory nurses were identified as the ones who provided the most valuable information.

Some participants were also concerned that hospitals, GPs and specialists did not consistently correspond so that information about their health was not shared. Others however, were pleased that regular letters went between the GP and the specialist.

“I only found out about lung function tests through ‘Better Breathers’”

Community services:

The point was made that you had to know the right person to ask for information about services in the home and that you then had to be able to ask the right questions. Just waiting for information to be provided was not going to be productive. While participants thought local council should provide more directory information about services in the locality they thought the information was often inadequate. There was also a strong view that GPs should provide information about services, even though there was a recognition that they were often the least likely to know of them. Better Breathers was identified by most of the group as a good source of information.

Oxygen home supplies:

One of the topics that most preoccupied participants was concerned with oxygen. There were problems with its delivery for two participants; having to remain at home until it was delivered meant that appointments might be missed, while another person had not received a delivery and had had to wait four days without an oxygen cylinder. For others there was lack of information about safe use of oxygen cylinders and for newer people lack of help and instructions to connect it. Reliance on the drivers for instruction and help was not seen as good quality service. While some drivers were kindly and helpful, none were professionally qualified to provide advice to people with COPD.

Emergency services:

The other topic that greatly preoccupied participants related to emergency services. People with COPD clearly felt anxious that there were times when it was hard to breathe and they were not confident that they would receive help in time. Some were not

confident in relying on the GP to identify when the person was having serious difficulties and it might be an emergency.

“You can’t leave it to the GP because they don’t have the right attitude-they put it in the too hard basket and send you home on medication.”

Most participants in this group were extremely anxious about how they would deal with an emergency as they had little confidence that help was immediately at hand. People who lived on their own were very anxious that they would not get an ambulance in time. Others who had had previous experiences of not being able to breathe knew they should relax but found this enormously difficult to do when on their own.

“We all have times when we need help, especially people on their own who are not coping. You get twitchy and panicky and then you need someone to support and help immediately.”

“You need someone to come to the house in an emergency-the ambos are good but they are not specialists in this area.”

Participants identified that there was a lack of knowledge in community services about COPD, so there was little appreciation of what constituted an emergency. Some of the participants had contacted ‘Nurse on Call’ but found the duty nurse ‘vague’ about COPD.

When participants were asked to design an ideal service that would cater for people with COPD, there were two features they all agreed on. One related to the need for more respiratory nurses and the other related to the need to make access to emergency services central. The respiratory nurse could perform the function of assessing the person’s level of need, and if necessary arrange for an ambulance or admission to hospital. There was no firm agreement on how this service would be organised, with suggestions that the nurse could be allotted a district to cover or she could be central and following assessment would alert other appropriate services. When there was no emergency she could provide information about support services in the home. Another suggestion that received strong support from other participants concerned the need for ‘rolling rehab’

“You need more than emergency services; you need pulmonary rehab. Rehab lowers your need for hospitalisation.”

While some rehab was available it was too general and not specialised for pulmonary problems. In addition it was not ongoing. One person considered the courses at Epworth Hospital where he had learned to deal with panic attacks provided an ideal model. While the Rosebud Rehab courses were good, they were sometimes cancelled due to lack of interest. Participants considered that this was partly due to the lack of knowledge of GPs who did not refer people to them.

Ongoing courses were important to teach people to self-manage. A small number of people in the group recognised that it was possible to manage their COPD by undertaking exercise programs, managing medications optimally and actively seeking information.

All agreed that information was an important component of any service. People with COPD required information about programs and medications and GPs required information to work effectively with them. Better Breathers was considered to be pivotal in providing information to people with COPD. Consequently Better Breathers and groups like it needed to be an intrinsic part of any ideal service.

“Better Breathers is a great way to get information. We have regular speakers and people are able to talk with one another about what services there are and what works for them. We’d like to help more people so we put out brochures and we have a newsletter. We’d like more support for our work from Peninsula Health and the GPs. We’d support Peninsula Health too.”

The group agreed that the internet was a good source of information if a person had access to a computer. In this group, the majority did not have that access and indicated that this was the case with others of their acquaintance.

When asked if the group considered that consumers should play a greater role in improving health services, there was enthusiastic response. Participants were pleased they had been asked to contribute to the focus group.

“It’s very important to include us—we know what we want, what we need to keep us going!”

“Services need to be user-friendly and this is a good way to find out. If the emphasis is on management they have to consult us.”

Rosebud Diabetes Focus Group

This group had five participants, one of whom was a man. Two of the women had type 1 diabetes.

Participants all saw their GP as a central point for diabetes care. All participants however accessed a range of other services, such as the practice nurse and the diabetes nurse educator. Most of the participants considered support groups held at Mornington and Rosebud as an important part of their own care. It was where they received up to date information and heard about any programs that were available. One woman had undertaken two courses with a diabetes educator as well as attending a Living Well program at Rosebud PCHS. Most of the participants were aware that they needed regular podiatry and ophthalmology check-ups. The local pharmacist was held in high regard by this group. He had undertaken a Home Medicines Review for one participant and provided her with a medication record; others relied on him for information about diabetes and for access to the NDSS.

One participant had started her care in the private system and had found it poor quality care, where staff were poorly informed about diabetes ; she was -bombardeðwith information and she was treated incorrectly as a type 2 diabetes patient. Additionally there were costs such \$90 per visit to see a DNE. More recently, having become a public patient, she now has difficulty accessing the community health services because she is working.

Coordinating services:

This was variable among the group. One woman relied on her endocrinologist to set up other appointments and remind her, while several relied on their GP to do this. Others preferred to control this aspect of their medical care.

Information about diabetes:

Participants had varying views about the availability of information. One participant considered there was a lot of information -out thereøbut it was difficult to know where to go to find it, while another thought there was little information and it was often conflicting. Participants varied on sources of good information about diabetes self-management. Some relied on Diabetes Australia-Victoria, some on local diabetes nurse educators and their GP and another on the local pharmacist. Support groups were also considered as being the source of good information, especially when the DNE had been in regular attendance.

Support in managing diabetes:

One woman considered that having her own routine was her most important source of support.

“I have a routine. I do my monitoring. I do my exercises and I make the corrections I need to keep myself on track.”

Others received support from membership in a support group, from their own families or from the GP.

One of the participants commented that when people, like her, were in full-time work it was not possible to attend the local support groups which traditionally met during the day. However, as a person with Type 1 diabetes she and others had created a type 1 support group that met in the evenings. This person argued that greater recognition of type 1 diabetes was important in the Peninsula catchment area.

When asked what should be included in an ideal service for people with diabetes, the group agreed that an ideal service would routinely provide education and training to all people when they were first diagnosed. Information included knowing about the availability of products as well as information on diet and exercise programs in the area. A centralised source of information would mean easier access. Members of the group varied on where information could be centralised. Some considered that support groups offered this level of centralisation, while others argued the GP was the obvious central point. Support group members identified the DNE as providing information to the groups

and were disappointed that the DNE no longer attended as often as in the past. The internet as a source of information did not receive strong support from this group. The local newspaper was identified by one person as a good source of information. She had recently found out about some exercise classes after seeing them advertised in the local paper.

There were also variations in the form that information should be provided. Some considered it should be written information sourced from a GP or a pharmacist, while others considered that one-on-one information was best because a person could return to ask questions.

Information and education at diagnosis however were not enough and continuing education was important to assist in self-management. One person with type 1 diabetes had undertaken the Dose Adjustment for Normal Eating (DAFNE) program which had provided her with the means to self-manage. Others required ongoing programs including exercise programs and information on diet, to support them in maintaining their routines. Some of these programs needed to be in the evenings, include childcare and be locally based to meet the broad community needs.

Rosebud depression and anxiety group

This group only had four participants, one of whom was a man in his 40s. One participant had recently been diagnosed with depression following the death of a friend she cared for. Her GP had referred her to the local community health service for counselling. The man had developed depression following diagnosis of early onset Parkinson's disease. He was referred by the GP to both a psychologist and psychiatrist. One participant had been prescribed antidepressants by the GP some years before and had not reacted well to them. She weaned herself off them. She regards her depression as environmental, that is, related to her role as her husband's carer. The other participant has lived with depression for many years. She has private insurance and considers that this gives her access to good quality care, as she is able to see better health professionals and see them more quickly. Her GP has also arranged a case manager for her so she does not have to worry about other services, such as domestic help from the local council.

Two of the participants identified that services were not well coordinated in the public system. Of particular concern was that personal information might be poorly transmitted between services, while another concern related to accessing services at home. One participant had not been provided with any help after discharge from Peninsula Health while another could not get the help to care for her husband, including respite.

“I went to hospital and was kept waiting 4 hours because of some mix-up with my records.”

There was a strong view from all participants that mental health services were poorly resourced on the Peninsula and this was largely due to it not being considered a health priority in the area. It was unlikely that any of them would be able to see someone quickly in a crisis. For one participant, there was the possibility of travelling to the city

while for others it was simply a case of waiting several weeks for an appointment or presenting at the hospital. Acute services were more available for physical conditions than they were for mental conditions.

“...if you break your leg you get to see someone immediately and it is treated immediately. You can't see depression.”

This lack of priority had consequences, where depression might be confused with another condition. Having been admitted to Rosebud Rehab (?) for an adverse reaction to penicillin recently, the man said that he was denied his medication for Parkinson's disease on one occasion and later when the staff forgot to give it to him they did not believe he was correct in asking for it. He considered that they ignored his requests because they were aware he had depression.

“I they just treated me like an idiot because they knew I also had depression...”

Another consequence of the lack of priorities was that a person with depression could end up in a general ward where everyone might know and not understand about depression.

Participants considered that stigma towards people with depression still existed and that this partly explained the lack of attention to mental health in health services. Overall, there was poor community understanding of how depression affected people leaving them unmotivated so that every day it was hard to get up and get going. Health professionals as part of the community might also not be aware of how depression affected people.

In a service that was specially designed to assist people with depression and anxiety the staff would be educated to respond. Incidents where the concerns of someone with depression were dismissed as just depression would not happen. There would be empathy and help rather than dismissal. One person suggested a specialist facility at Peninsula Health where all the services were centralised, including CAT services and outreach services.

“...part of the hospital where you are understood and can relate to other people, where you can get confidence. Being with others helps you back on your feet.”

This specialist service would be graded so that a person could receive care for severe depression, then move to an education and support section and eventually have rehabilitation and go home. A specialist nurse would visit each person on their admission and assess the level of their needs.

A service would include an outreach service such as a telephone line: The need to have someone who listened during a crisis was important. It could mean the difference between suicide and the motivation to continue.

“A kind of Lifeline for depression would be good”

Support groups should be integral to a specially designed service. Support groups could be the place to provide education and information to clients. They also provide a place where a person feels comfortable with other people who understand.

“From the first time I went I felt really comfortable with other people because they were fellow sufferers and knew how I felt.”

In addition to a specialist service participants recommended more community resources such as CAT teams, better public transport and more bulk-billing GPs.

Mt Eliza COPD Group

There were six participants in this focus group, two of whom were men. Participants all saw a specialist and a general practitioner regularly. Three of the participants were on oxygen permanently, while another participant used it at night. Older participants also received some domestic help such as assistance with housework and shopping. Most participants were also members of groups, largely Lungnet and Better Breathers, where they received information and sometimes undertook exercises.

Discussion in this group moved to the importance of maintenance programs for COPD. Rehabilitation was important but it was only a start. Continuing exercises were essential. One man, who had only recently moved to the area, recounted how he had previously attended a respiratory group in the Eastern suburbs. Attending every week over four years he undertook strength training, and exercising. Now in the Aspendale area, he was attending an exercise class run at a rehab centre.

“I need this kind of support. There are only about four of us, but it makes me pull up my socks. If I can't do something like this for months then I start to lose condition and then I lose confidence and then I turn into a blob.”

There was agreement amongst the group that programs such as these were excellent means to maintain breathing because of the support they gave people, but there was not a lot of evidence that others were attending such groups regularly. A woman who was participating in her capacity as the carer of her husband said he was frightened to attend rehab and could not keep up with the Better Breathers exercises so that he did not go. He had attended an exercise class at Rosebud where he felt he could manage.

The group discussed their perception that specialist and general practitioners services were not of a high quality for COPD. Some considered their specialist lost interest them once they went to rehabilitation largely because there was not a lot more specialists could do. Others thought that they were so specialist they ignored important complications, such as blood clots on the lungs. Older participants felt they were not important to the specialist because there was so little that could be done for them.

“He's not that interested because I have about 2 to 5 years to live and there's not much more he can do.”

This sense of abandonment was reinforced by the poor listening skills of some specialists that the participants had experienced. One woman had told her specialist she was struggling and he had responded by telling her to return in 6 months. Another had had concerns about the effects of cortisone which had not been addressed.

General practitioners were seen as relatively poorly informed about COPD and the services available to people with COPD. However there were exceptions with one GP coming to the house to wait with the person for an ambulance, while another participant found her GP very helpful.

Participants considered there was a lack of communication between the specialist and the GP. There was a sense that little information was shared between them and they did not communicate with any other health professionals such as physiotherapists. One participant had urged her GP to provide her with a care plan as she considered it an essential part of her care. Other participants were unaware that plans were available or how they could improve health.

Most participants did not see the GP as their main source of information. One participant sourced services through DVA, while another found that Peninsula Health was a very good source of information about medication, how it worked and potential side effects. Other participants found information from Better Breathers. One woman complained that she had information but she was not eligible for council services because she was too young to receive aged services and the council did not recognise her needs because she had emphysema. Others challenged this notion but she maintained she would be refused services from the local council were she to apply. This lengthy conversation underscored the need for better information to this group about services.

Participants were all concerned with loss of independence. One participant who is 84 found her inability to undertake any household tasks very frustrating and depressing, another elderly participant found a scooter provided her with more independence as she could now shop. Others considered regular exercise assisted them in being independent. The woman who considered she was not eligible for services relied on friends to help her with housework and shopping and was clearly depressed by her dependence.

It became apparent that self-confidence played an important role in maintaining independence. Those who attended exercise classes regularly had more confidence in their own abilities. It was agreed that an ideal service for people with COPD would include weekly exercise classes, which would be an integral part of an individualised care plan.

“A weekly exercise class that’s appropriate for the person’s ability because some of them aren’t that good and you lose confidence. They are also good for socialising and you need that with COPD because you become so limited in when you can get out.”

Information was also considered an essential part of any service.

At the end of the focus group, this group of people all exchanged names and phone numbers in order to keep in contact with one another.

Mt Eliza Diabetes Focus Group

Seven people attended this group, four of whom were men. One woman was the carer of her 18 year old son, who has type1 diabetes. One woman participant had type1 diabetes.

Participants regularly saw their GP, with several attending the endocrinology unit at Frankston Hospital for specialist services. Others saw endocrinologists on a three month, six month basis privately. Several participants noted that they regularly saw a DNE, podiatrist and ophthalmologist through Integrated Care Services. Two participants attended Mornington Diabetes Support Group regularly. The mother of the young man with diabetes said her son who is now 18 had attended the Paediatric Diabetes Unit at Frankston Hospital for 11 years now. He had received æterrificøcare from that unit but was now preparing to make the transition to adult care, which she felt would be a smooth transition. The woman with type 1 diabetes explained that she received two different types of services; when she was pregnant she was eligible for public services and when not pregnant she reverted back to being a private patient.

Generally participants reported being very pleased with the quality and the quantity of the care they received. Most had good relationships with their GP, with one exception:

“I have an ulcerated foot and the GP was most unhelpful-so now I am looking for another GP.”

Services such as the Diabetes Nurse Educator were considered excellent sources of information. All services from Peninsula Health and Integrated Care Services were held in high regard.

“I see a podiatrist and a diabetes educator at Integrated Care at Frankston-they do a great job! I’ve been to Casualty at Frankston and they were really good too!”

Private specialists however were a particular source of frustration, largely because of the long waits in between appointments and their inflexible times. One participant told the story of her brother who refused to take time off work to see a specialist though his diabetes was uncontrolled. People who worked were not well catered for. Others noted that difficulties getting appointments was not limited to specialists; the same could be said for some GPs and for hospital outpatients.

Participants had had mixed experiences with coordinated care and shared information. Several participants reported that the pathology labs had not sent information back to their GPs. Others had trouble with referrals, one person citing that a referral from the clinic to another service only lasted 3 months so that she had to use time and money to

get new referrals. However, those who attended Integrated Care were pleased with this aspect of their service where it was easy to organise appointments and the services were centralised.

Similarly participants had mixed experiences of obtaining information about their diabetes and the services. One participant considered that getting information was difficult and that the information itself could be inconsistent. The DNE was the most important source of information.

“The more access to a DNE, the better the information.”

For those who attended Integrated Care, Frankston there were more opportunities to access information than those who relied on GPs and/or specialists.

Where people relied on GPs or specialists there should be a system imposed to force them to provide information and referral to other appropriate services.

“One of the problems is that GPs are not aware of what is available in diabetes services in the hospitals, so they don’t refer people who would benefit.”

All new patients should receive an information pack as a matter of course, no matter who undertook the initial consultation. Some of the discussion acknowledged that information only reached those who wanted it. Where people were in denial they could avoid receiving information.

The importance of information to people with diabetes in the community became apparent when the young woman with type 1 diabetes thought she was ineligible for public hospital or community health services for her type 1 diabetes because she was too young and also had private health insurance. Others explained to her that she did not have to pay \$200.00 per visit to a DNE if she chose not to.

Discussion continued on the need to know about medications. One person had listed his medications on a card which he kept in his wallet. Another had a printout from the chemist. Both did this to have a record in emergencies. There was some agreement, though not a consensus that electronic health records would help regarding information, appointments and other matters.

Participants considered that ideally information should be available from a central point. DNEs could serve as such and would refer out to all other allied health specialities. A central information service would assist GPs as they could also use it to find services for their clients. People who were newly diagnosed could receive an information pack to prepare themselves to attend clinics and ask questions.

There was broad agreement that patients and GPs would benefit if the GPs were connected to the hospital. Connection meant that the GP would know of the hospital’s activities and refer people with diabetes to the ones s/he considered relevant.

“The hospital had a session on pumps and my GP knew about it so he phoned and got the information about the pumps and gave it to me.”

Continuing education was also seen as central to building up one's ability to self-manage. Education sessions provided the person with the knowledge to monitor their diabetes, understand warning signs and change attitudes towards their diabetes.

“Yes, that kind of education session is very important. That's how you learn to self-manage, you learn the consequences of ignoring the warning signs---when there is the information then the power goes to the patient. It does require work on your part but it is important to change your attitudes once you have to manage your diabetes.”

This led participants to consider that support groups were central to self-management. They offered opportunities for information as well as opportunities for group exercise and walking and ultimately social contacts. The problem with them was the lack of flexibility, since the closest one was Mornington. It was not always easy to go to Mornington from other areas of the Peninsula during the day, especially as public transport was not good in the area. Other people who worked also found it difficult to attend support groups.

Mt Eliza Depression and Anxiety Focus Group

This group had six participants, two of whom were men. Of this group, two participants, a man and a woman were younger adults.

The use of services by participants varied from person to person. One participant had been in a hospital in Prahran several times over the last 18 months, and was now attending Peninsula Support Services (PSS); another had been an inpatient at Frankston Hospital following intervention from the CAT team. Another participant had received help from PenDAP at Peninsula Health, was in a group counselling session and had been referred to PSS. One participant attended Melbourne Clinic as a private patient. Most participants saw a psychologist or psychiatrist as part of their care. Two of the participants indicated their GP was central to care of their depression, while several had outreach support services. .

All the participants had long and convoluted histories of depression and their relationships with the health system. However, most appeared to have arrived at some degree of resolution, at least temporarily, in their lives and were looking towards their futures with some optimism.

“I've been going to PSS for the last three years...I can't criticise them, they are very good. I'm nearly OK now.”

“I tend to talk things over with my outreach worker from the Melbourne Clinic. It's been important for me because they help set goals, and help achieve them.”

“I’m back to doing normal things again-cooking, tennis, playing with the pets. I couldn’t do that without medication.”

One participant was not at this point. She had recently been discharged from Frankston Hospital where she had been admitted to a dementia ward, suffering anorexia and feeling suicidal. She considered she was well treated but said had she not been a nurse and used to dementia she would have been far more frightened. Now on medication, she still felt very depressed, unable to find relief from a sense of impending doom and was just making it through each day.

Participants’ experiences of services profoundly affected their recoveries, as well as their future use of services. All of those who had been referred to PSS had found it extremely helpful and were staying with the service. The participant who attended Melbourne Clinic did so because she had found being an inpatient at Frankston incoherent and unstructured.

“I hated it because they would not let me leave but they got rid of me as soon as possible...It didn’t help me with any self-development... I felt I was treated like a piece of meat”

Another participant had no complaints about his admissions to Frankston Hospital on two separate occasions. It led him to undertake some courses with Peninsula Health and to have regular visits from the psych nurses. But adverse experience of a medication prescribed by a psychiatrist had the following consequences:

“I haven’t seen him since. I struggle on, on my own.”

Another participant’s experience with a psychiatrist had a different outcome:

“My first psychiatrist, I sacked after a week. He made me feel sick! The next one was tops! If they are bad they are powerfully bad and if they are good the good is powerful!”

One woman had thirty five years experience of mental health services on the Peninsula. Initially she had had ECT and had been in Frankston Hospital for some years. She was later sent to a nursing home, though she was relatively young. A referral to another psychiatrist led to her to rehabilitation and returning to the community, where she now lives independently but is relatively isolated. She now attends some courses but has difficulty accessing them because of the poor public transport.

Once again, experience of GP services varied from person to person in the group. One participant considered GPs were not likely to have any understanding, while another thought younger GPs were more skilled at listening. Several of the participants had good GPs they found extremely supportive.

“My GP is sensational; she’s engaging, empathic, gives full attention, not looking at her watch all the time and she gives practical advice!”

Those with poor experiences of GPs considered they were unlikely to listen and most likely to send them off to a psychiatrist, who was most likely to prescribe medication.

All participants identified they needed someone to talk with on a regular basis. Some saw a psychiatrist or psychologist for this, while others went to PSS. Some did both. Outreach workers, psych nurses, counsellors and support groups were all extremely important adjuncts. Where there was no crisis, these supports played a greater role than clinical services but relationships with individuals were very important. .

“The personality of the doctor makes a big difference in mental health”

“The hardest thing is to find the right help and the right person.”

“It’s crucial-you need to have mutual understanding, they have to act in your interests and help you make informed decisions.”

Social contacts were also important. These came through involvement with group activities in PSS, including outings and support group sessions. One participant claimed that group sessions he had found from the Menø Referral Line were a -life-changingø experience. He was also attending a menø shed which gave him the opportunity to learn life skills such as cooking, gardening and òjust talkingö.

“That’s the sort of back-up help you need to get back to normal.”

Finding out about all services was difficult. Some people only found out about PSS by word-of-mouth; another participant found out about services from the Yellow Pages. GPs did not seem well informed about services for depression. Another participant had relied on her mother to find out information about services. She knew it helped her mother by giving her a role to play, but there was general agreement that when people were on their own as well as being depressed, it was hard to locate services.

Similarly, there were views that some services were not well-coordinated. GPs did not refer to anybody much other than psychiatrists. In longer illnesses when psychiatrists had retired histories had disappeared. Both public and private hospitals were favourably viewed in terms of coordinating services.

This group recommended centralised information about all services for depression and anxiety. It was particularly important to have access to more supports to assist people reintegrate into the community. Part of this related to the need to improve public transport so that people with depression and anxiety could get to them. Services for men such as more menø sheds were another priority as there were few activities to assist men who were depressed.

Hastings Focus Group

This group was organised to provide an opportunity for people living in the Westernport area with COPD, depression and anxiety or diabetes to contribute to the consultation. Only two men out of an expected five participants attended. On this basis, the session was closer to being a semi-structured interview.

Both of the men, one elderly and the other middle-aged had COPD. The younger man was also being treated for depression and attended PSS. .

The older man initially said he used no services other than the GP but he later mentioned he attended a specialist several times a year. He and his wife had moved from Tasmania, and only recently settled in Hastings. He explained that services in Tasmania were organised differently and the lack of knowledge of how they were organised in Victoria left him at a disadvantage. He was looking for a new GP because the current one knows little about COPD or any services an elderly couple might be eligible for. He had lost confidence in the GP who continued prescribing antibiotics for an infection even though the antibiotics were doing little to help.

The younger man had only recently moved into the Hastings area. He had seen a GP and specialist at Mt Eliza but had recently contacted new ones in Somerville. He described his health as a vicious circle. Regardless of how much he tried to prevent it, his COPD reached a point where it was necessary to call an ambulance and go to the ED at Frankston. This was always distressing, having been a health professional who had left work following an assault, hospitals made him very anxious and he had signed himself out on one occasion. He felt that this behaviour had led to poor care on subsequent occasions. He always delayed as long as possible before he went to ED. Only recently, he had experienced difficulty breathing and had panicked and collapsed at home. His partner came home early and took him to the ED. He explained that his medication and nebulizer were not enough sometimes and he required oxygen, which he got at the ED. His biggest fear now was that he would be alone at home and not able to breathe. He would not have time to call an ambulance for himself.

Both men felt that they suffered from poor communication across the health system. There were problems with information sharing between the GP and the patients, which included the quality of communication. There was a need for more careful and accurate communication of information. At the same time neither man had been given any information on what they should do in an emergency, and neither had received a care plan. Both relied on tell-tale signs to call the ambulance.

Neither man was aware of any other services they might access. One had heard about dental care as an EPC item and had had to get the information from the internet as the GP was not aware of it. The GP wrote out the referral but the man had to pay upfront so he could not afford the service. The younger man had heard about EPC items but did not know if he was eligible or how to access them.

The older man said that both he and his wife required help in the home: with cleaning, maintenance and gardening but did not know where to get it. Whenever they inquired there was a cost involved. He had also had some services from the Community Health Service but no longer accessed because of the waiting lists. The younger man had not known of the community health service's existence until today. He did not think he was in a category to be eligible for any help.

Both men considered that the health care would improve if they had an emergency care plan and an oxygen cylinder for emergencies. A respiratory nurse on call to give advice or get emergency action when there were signs that 'something' not working would also be a great comfort.

The older man thought a support group would also be helpful. He had heard that there was one in Rosebud. When he mentioned this, the other man was very interested and wanted to know more. They were both interested in attending the group but concerned that it was too far away to go on a regular basis. They thought it would be valuable to hear of any services and to meet other people and find out how they coped with COPD. When it was suggested that they might be able to form their own support group, they thought this might not work since they had met no others in the area who had COPD.

4. RESULTS OF THE SURVEYS

4.1 COPD Survey

There were 21 responses to the COPD survey, the larger proportion of who were from Cranbourne, Mornington and Rosebud. Most were in the older age groups and were married. Heart disease was the main condition other than COPD reported by this group. The majority of the group received care for their COPD from their GP, with the specialist also being a strong contender for care. Allied health professionals and the hospital were ranked third and fourth in priority by a small number of the survey group.

Nearly all the group were 'mostly satisfied' or 'very satisfied' with the care they received, some responding that their doctor was extremely responsive and dedicated.

Similarly nearly all the survey group considered COPD has had a 'big' or 'major' impact on their lives. This was reflected in the need for other services such as oxygen, 'meals on wheels' and home help, as well as being limited in undertaking some tasks such as housework and shopping. People in the survey identified they would like more rehabilitation services, with one person commenting s/he would like to have a refresher program; self-management programs and assistance with transport. Some services were difficult to access because of the costs and others because people had not been aware they could use them.

Largely, getting information about all services was seen as difficult. Half the survey group said they would not know where to seek information. With regard to information about health services everyone approached the GP, while some also saw the specialist and to a lesser extent the hospital as a source of information. This pattern was also

reflected when people sought home help services with the addition that some also approached the local council. Seeking information in these manners was very satisfactory to the majority of the survey group.

When asked how local health services could get more information out to people with COPD, there were suggestions to use newsletters, to provide information in face to face settings and by providing information to support groups.

Suggestions to improve services for people with COPD included:

- More support groups and advertisements;
- GP home visits for home bound individuals;
- Explaining to the community what COPD is;
- Support groups such as 'Better Breathers';
- More public seating to be made available for people with COPD;
- Electric scooters in shopping centres;
- Counselling and psychiatric help for people with COPD;
- Informing people with COPD there is a respiratory nurse in Hastings.

4.2 Diabetes Survey

There were fourteen responses to the diabetes survey. While the majority were in older age groups there were also some people in early and late middle age. Respondents were largely from Seaford and McCrae. More than half of them were married. Anxiety and depression and high cholesterol were the most reported co-morbidities, followed by high blood pressure and COPD. The majority of the group relied on GPs, the hospital and specialists in that order of priority. A smaller number rated allied health professionals as those they most used. The comments here provide some clues as to this pattern of usage with one person saying s/he knew enough not to need to see anyone else (perhaps apart from the doctor), while another person said that it was good to see the educator between the clinical visits. Another person underscored the value of the community health service in providing all the health checks as well as a diabetes educator to provide information at support group meetings. This broad service usage was better reflected in the answers people provided to the question about the services they used other than medical services. Survey respondents demonstrated they made use of nurse educators, podiatrists, dietitians, dental services, ophthalmologists and pharmacists.

In this group, people did not feel that diabetes was having a big impact on their lives, with more than half reporting 'none' or 'small' impacts. Few people reported having difficulty accessing the help they needed, though one person would like to know there was an educator for weekend access and another wanted a support group where the educator attended. The majority of this group relied on the GP to get information about health conditions, followed by the hospital. The internet was also a source of information. The GP was also a source of information about home help services as was the hospital and the internet. Most people were very satisfied with the quality of the information they had received, though it is worthwhile noting that one or more of the survey group were disappointed and expressed the view they had not known where to seek information.

Newsletters, brochures, face to face information and the internet were all seen as important means to provide information to people with diabetes. Additionally written information to people at subsequent visits as well as presentations and written information at support groups were also valuable.

Suggestions to improve services include:

- A clinic closer to Hastings;
- Better knowledge on Type 1 diabetes in the ED at hospitals;
- Before we moved to Hastings we attended a Community Health Service in Darebin where we had monthly meetings with a DNE who kept us up to date on medications, recipes and foods as well as guest speakers and a yearly review with the podiatrist, etc-all this at reasonable cost!
- Upgrade the Diabetes Unit-they have not had extra staff even though they have extra patients. That's why we go private even though we cannot claim;
- Diabetes professionals' arrogance, general lack of knowledge is very disappointing. All diabetics should have their kidneys tested for signs of damage and specialists should have consistent ideas of what constitutes kidney damage.
- Access to diabetes specialists so that I don't have to access the ED.

4.3 Depression/anxiety survey

There were seven people involved in this survey, with most questions answered by six of them. Most people were in the older age groups, with the largest number from Rosebud. Half the group was single. The group listed other co-morbidities as diabetes, sleep apnoea, COPD, reflux and high blood pressure. While the majority relied on the GP for their health care, some listed community health services and specialists as their first source. The majority were 'very' or 'mostly' satisfied with the care they received. This was underlined by the comment where one person said that having built up a relationship of trust with the psychologist it was now hard that she was going on maternity leave. Depression/anxiety had a big impact on the survey group's lives with most reporting its impact relating to their ability to socialise and contribute to community groups.

Members of this group reported they had difficulty accessing counselling, dietary advice and rehabilitation services. Partly this was due to not knowing where to seek the services, the costs involved and concern over their quality. While the GP was the main source of information about health conditions this group also used the internet more extensively than the other groups did. However they were also more likely to contact the local council about home help services than the other two groups surveyed. Their satisfaction was lower than the other two groups.

Newsletter and brochures were considered the best means to provide information to people with chronic conditions, with the internet also being considered valuable.

Suggestions to improve services include:

- Health professionals should keep in touch via letter, phone calls to show that someone cares;

- Reduce government payment to allow people with chronic conditions to stay in work;
- A social group run by a positive and happy person as many depressed people are lonely;
- Help should come from within the family so family members need education on how to communicate with someone with depression;
- Doctors' attitudes are very important-often view it as something to get over;
- Reduce the cost of healthcare as costs increase the stress;
- More reading matter as I wasn't aware of how common the problem is;
- Better community understanding of depression;
- Mental is a degrading word-use kinder words.

5. PRIORITIES IDENTIFIED BY THE FOCUS GROUPS AND SURVEYS ACCORDING TO CONDITION

In this section we consider the priorities that each illness group identified across all the focus groups. These priorities reflect the level of agreement across the groups. They are listed from those issues or priorities that had the most agreement across the groups to those where only one or two people thought they were important.

COPD Focus Groups and Survey

Table 2: Priorities of people with COPD (all groups)

Priorities in order of significance
Emergency services including personnel and information
Information about all services
Safe oxygen usage instruction and its availability.
Support groups integrated into care
Exercise groups or rolling rehab
Better informed health professionals
Better communication between services
Transport

Participants in all of the COPD focus group (Rosebud, Mt Eliza and Hastings) were anxious about what to do in the event of an emergency. There was generalised anxiety that assistance would not be immediately available if they were not able to breathe. Ending up in the ED of a public hospital was not something participants thought desirable. These concerns dominated two of the focus groups, but were less important in the third. Lack of information about services such as help in the home, Enhanced Primary Care items and eligibility criteria was also a dominant concern. For some people oxygen usage and oxygen availability were anxieties. This level of anxiety was not reflected in the survey, though the great impact that COPD had on the lives of those surveyed suggests it might be there.

Support groups such as Better Breathers were considered to be very valuable as sources of information, activities and social support. Their role would be better understood if more health professionals were involved in them. Exercise groups or rolling rehab were seen as important adjuncts to treatment but were not necessarily readily available. This need for support groups and rehab was also reflected in the survey.

Health professionals, especially GPs were not well-informed about COPD and the services people with COPD required for their independence. Some people with COPD had experienced poor communication between services such as hospitals not informing their GPs about recent admissions.

Participants in the COPD groups suggested that improvements to services could be made by providing more exercise groups or rolling rehab to all those who wanted it. There was also a strong view that information should be available from a central point so that everyone knew where to go to find it. Centralised information regarding emergencies would also be a great improvement. Some participants considered that a centralised model could be evolved around a respiratory nurse. In this model the nurse would be the central point to assess an emergency, to address an emergency, to provide information about services and give emotional and practical support.

Finally transport was an issue for people wanting to access services from other parts of the Peninsula.

Diabetes Focus Groups and Survey

Table 3: Priorities of people with diabetes (all groups)

Priorities in order of significance
Information about all services
Integrated services
Support groups as part of a more integrated service
Centrality of the DNE
Problems of flexibility for younger people with T1D
Transport

Self-management was an underlying assumption in all the discussions about diabetes care. Participants saw the need for information about services as tools to assist them manage their own diabetes. Participants gathered information from different sources; some from the GP, others from the specialist, others from the pharmacist. Those who accessed Integrated Health Services were clearly better informed and could more easily access all the services they needed. Most people with type 2 diabetes belonged to a support group and were very appreciative of the value of having the DNE as part of the group, since it was a valuable means to access information and expertise. This was reflected in the survey group, where the importance of a DNE attending and presenting at a support was considered essential.

Younger people with type 1 diabetes who were working were not able to access support groups and some other services. They were less able to access information than the others. One of the participants had recently addressed this situation by starting an evening support group for people with type 1 diabetes. The internet was used by people in the survey to access information.

When asked about improvements to services for people with diabetes there was a strong consensus that information about services and integrated services underpinned self-management of diabetes. Improvements would be a centralised service for information where all people were able to access consistent information. There was also a strong consensus that well-informed health professionals were important, the most pivotal to self-management being the DNE to who people with diabetes should have greater access. Participants were aware that a DNE could be extremely busy and considered regular attendance at a support group by the DNE would assist with this level of access.

Depression and Anxiety Focus Groups and Survey

Table 4: Priorities of people with depression/anxiety (all groups)

Priorities in order of significance
Information about all services
Support services and support groups
Integrated services in area for people with depression/anxiety inc outreach service (specialty nurse)
Graded services
Better informed health professionals/community
Better services in public hospital for depression/anxiety
Transport

People with depression and anxiety wanted information about services, including community services. Having depression/anxiety made it difficult to find services oneself. Because of the stigma attached to having depression/anxiety support services such as PSS were highly valued. There was recognition that services needed to assist the person reintegrate back into society and from this perspective the services needed to be graded so people could move from dependence to independence.

Both the focus groups and the survey suggested that health professionals needed to understand depression and anxiety better especially if the person was receiving care for another condition. Health professionals who worked with depression and anxiety needed special qualities of patience and empathy to build an individual relationship with their clients. Several participants considered an empathic service was lacking at Peninsula Health Services but this is low on the list as it was not a universally held view. Transport needed to be improved so people could access services across the Peninsula. Lack of public transport might mean some people were socially isolated

Improvements that people in the focus groups suggested, to services for people with anxiety and depression included better integrated services with information, support and outreach services to contact in an emergency. More resources were required for mental health services on the Peninsula. Both the survey and the focus groups considered there was a need to improve the community's attitude towards people with depression and anxiety; the poor understanding by health professionals of the problems of people with anxiety and depression reflecting the poor understanding of the wider community.

6. CONCLUSION

The groups compared

Overall, of all the three illness groups those with COPD appeared to be those most anxious and concerned about the management of their condition. In individual cases, such as the two men in the Hastings area, the lack of information and lack of services indicated that this anxiety was realistic. These individuals appeared to lack essential services and information that consequently exposed them to a high level of risk. The reliance on emergency services, including ambulance staff and ED suggested that they had not been exposed to appropriate amounts of rehabilitation and exercise programs that would ameliorate their level of risk. Certainly in the event of their condition deteriorating, they had little idea of what help was available. The relative isolation of people with COPD was evident when at the end of the groups at Mt Eliza and Hastings all the participants exchanged names and phone numbers in order to remain in touch.

Participants in the diabetes groups appeared to be the ones who were best informed and most confident of managing their conditions. While each person accessed varying locations and services, both information and services were readily available. It was possible to find new information or to access a course or exercise group. Participants had access to services from the state-wide Diabetes Australia-Victoria, the national NDSS, hospital-based services, primary care services including community health services and the general practitioner and the local pharmacist. Younger people with type 1 diabetes were a special category who had less access to services because they worked. They reported they were more likely to be at risk in their care, because of confusion in health services between type 1 and 2 diabetes. They sought information from different sources to those with type 2 diabetes: either health professionals they worked with, Diabetes Australia-Victoria programs or the internet.

People with depression and anxiety in the focus groups were those most concerned to establish a relationship within an empathic service. Where this took place was less important than the empathy they received. Public, private or community-based services were all accessed, with individuals choosing the ones that suited their needs. For some this was a long and painful search, while others only found a service fortuitously. One of the hallmarks of a good service for this group was its ability to assist the person reintegrate back into the community.

The survey demonstrated that all the conditions had a strong view that more information about services should be shared with people with each condition and the community

generally. Newsletters and brochures were generally seen as the most informative, probably because people could return to reading them. Information provided through support groups was also another important means to communicate information about services.

At the same time, survey group members from each of the three conditions considered that information received face to face was a valued means. This means of receiving information was probably reflected in the high reliance on the GP to inform them about all manner of services with a high satisfaction rate with the GP in doing this.

The key issues revisited

- **Local examples of pathways for consumers to navigate from one service to another.**

All groups arrived at their own accord at a view that there should be a central place to access information. This would provide the basis of pathways to navigate from one service to another. Models of a central service were varied. Some saw it as community-based such as the information held by a support group, where health professionals would refer all their clients. Others saw it centralised in a person such as a respiratory nurse or DNE. Some saw it as the role of the hospital. The information that would be held in a centralised service related to information to manage a health condition and this could be quite specialised information and information about the full range of services including health and community services. Each group considered a centralised service should be specialised to their condition, rather than a general information service.

There was poor support for information to be electronic; most people wanted information to be based in their locality and accessible by traditional means of speaking to a person by phone or in person. Those who accessed information from the Internet saw this as a second-best option.

- **Experiences of both primary and acute care services**

Views of the services available on the Peninsula varied among individuals rather than between groups. Some participants found their general practitioners helpful while others relied more heavily on their specialists. Some people with depression/anxiety considered that public services, including acute care were generally poor quality while others regarded it as very helpful and had experienced a good level of integration and community outreach. Generally, participants considered that community health services across the Peninsula provided good services. Surprisingly, waiting lists for services received only an occasional mention and did not seem to be perceived as a great problem. Many of the services available in community health such as exercise groups and counselling were held in high regard. There was some confusion amongst group participants of where services were located following the demolition of the Rosebud site.

Only a small number of people considered their care had suffered because of poor communication between health professionals. Most frequently mentioned were that specialists or the hospital did not keep the GP informed. Some people considered their

health had suffered because the GP or the specialist were poor communicators with them and did not listen properly. Lack of knowledge of services amongst GPs and specialists was a source of frustration. People with COPD were those most likely to consider these issues of communication to be poor quality.

Support groups were universally held to be central to health care and maintaining a good quality of life. Support groups were seen as a good vehicle for maintaining self-management strategies, by supporting the individual to keep up their regime. Support group members wanted the value of the groups to be recognised by health services and for support groups to be considered as part of the overall care of a person with a specific condition. There were calls for more referrals to support groups, more recognition of the work of support groups, and opportunities to publicise the work of support groups through distribution of brochures and meeting dates. One of the means to ensure that support groups were integrated into health services was regular attendance and presentations by health professionals.

- **Consumer and carer understanding of the principles of self-management, care coordination, comprehensive assessments and care planning and experiences of self-management interventions**

While people with diabetes understood the basis of self-management and could access programs that helped them maintain their own self-management regimes, people with COPD and depression/anxiety revealed no such understanding. This was particularly evident with people with COPD who did not routinely access exercise classes or programs to deal improve their breathing so they improved their control. Those who had accessed such programs had generally done so outside the Peninsula Health area. People with COPD in the focus groups were more likely to rely on emergency services. People with depression/anxiety generally seemed to have access to the support they required, though they had searched to find suitable support services. They did not however demonstrate they had an understanding of strategies to assist them deal with depression/anxiety beyond this, such as working to prevent further episodes of depression/anxiety.

While some people knew of EPC items only one or two focus group participants had a care plan. They did not necessarily see this as a means to plan for long term objectives of improving their health, rather it provided access to some primary care services they needed at the time.

- **Transport problems**

Transport problems on The Peninsula were mentioned, but less than expected. There were long distances to travel for some services, especially attending support groups. For those who could not drive, the lack of public transport meant they did not access some services. People with depression/anxiety were less likely to access volunteer transport since they felt compelled to explain why they required it. No-one had any solutions to offer.

- **Consumer consultations**

Finally, all participants in the focus groups were pleased that Peninsula Health was undertaking this consultation. Some expressed the view that Peninsula Health was always consultative and this was another part of that process, while others saw it as a chance to express their view on specific changes. Rarely did people speak in terms of complaint. Participants considered that had contributions to make to improving services through their suggestions and were prepared to assist Peninsula Health argue for more resources to help others on The Peninsula.

7. RECOMMENDATIONS

- Provide self-management programs to people with COPD and depression/anxiety to underpin the ability to cope in the community, avoid unnecessary emergency episodes and crises.
- Explore models of information provision such as a central model to underpin self-management and to provide a clear pathway to care. Information provision covers all services including health and community services.
- Adopt the suggested forms of information provision such as newsletters, brochures and face-to-face and evaluate these for their effectiveness.
- Integrate patient provided support services into health care.
- Utilise support groups as a means to provide information to groups of people.
- Provide opportunities for improved communication between health professionals and between health professionals and consumers.
- Support greater use of care plans by GPs in order to provide more access to services to underpin community care and self-management.
- Support continuing education of health professionals and community services on the needs of people with chronic illnesses.
- Build on the strong identification of consumers with specialist nurses such as respiratory nurses and DNEs to promote community-based care and self-management.

APPENDICES

APPENDIX A. Survey Questionnaire

Age

Suburb

Marital status

Other than (condition) do you have any other conditions?

Where do you go for medical care of your (condition)?

How would you rate the medical care you receive?

How would you rate the effect (condition) has on your life?

Other than medical services do you receive any other services?

Are there any activities you are unable to perform due to your (condition)?

What help or support would you like to receive but have not been able to receive?

Why haven't you been able to get this help?

Where do you go for information about your health condition?

Where do you get information about the services you need at home?

How satisfied with the information you have received from these sources?

How do you think local health services could get more information out to people with chronic conditions?

APPENDIX B. Results of each survey

B.1 Survey of 21 people with COPD

Age

0-10	0%
------	----

11-20	0%
-------	----

21-30	0%
-------	----

31-40	0%
-------	----

41-50	0%
-------	----

51-60	1	5%
-------	---	----

61-70	4	19%
-------	---	-----

71-80	9	43%
-------	---	-----

81-90	5	24%
-------	---	-----

91-100	2	10%
--------	---	-----

Total 21

Marital Status

Married	12	57%
---------	----	-----

Single	2	10%
--------	---	-----

Divorced	2	10%
----------	---	-----

Widowed	4	19%
De Facto	1	5%
Total	21	

Suburb

Mornington	3	14%
Hastings	1	5%
Chelsea	1	5%
Rosebud West	2	10%
Mt Martha	1	5%
Portsea1	5%	
Cranbourne	4	19%
Seaford	1	5%
Rye	1	5%
Shoreham	1	5%
Somers	1	5%
Dromana	1	5%
McCrae	2	10%
Cheltenham	1	5%
Total	21	

Conditions as well as COPD

Diabetes	2	10%
Asthma	1	5%
Heart Problems	6	29%
Parkinson's	1	5%
Back pain	1	5%
Coeliac	1	5%
Lung Tumor	1	5%
Emphysema	2	10%
Ileostomy	1	5%
Prostate	1	5%
Depression	2	10%
Kidney Probs	2	10%
OP	1	5%
High Chol	1	5%
Cervical Fusn	1	5%
Osteoarthritis	1	5%
High BP	1	5%
Total	21	

How Do You Rate Care Received

Very Satisfied	13	62 %
Mostly Satisfied	7	33%
Service good may be better service	1	5%
Total	21	

Impact on Life

No Impact		0%
Small Impact	1	5%
Makes Big Difference	11	55%
Major Impact	8	40%
Total	20	

Other Services Used

Podiatrist	6	29%
Ophthalmology	1	5%
Exercise Classes	3	14%
Dental Services	5	24%
Support Group	6	29%
Rehab Courses	3	14%
Pharmacy	11	52%
Nursing	1	5%
Other	8	38%
Total	21	

Activities Unable to Perform

Housework	15	71%
Shopping	12	57%
Gardening	15	71%
Driving	5	24%
Home Maintenance	20	95%
Socialising	9	43%
Community Gps	12	57%
Personal Hygiene	6	29%
Total	21	

What Help or Support would you like?

Nurse Ed	2	10%
Podiatrist	3	14%
Dietitian	2	10%
Exercise Classes	1	5%
Dental Services	1	5%
Social Welfare	1	5%
Respiratory Nurse	1	5%
Rehab Courses	4	19%

Self Mx Programs	3	14%
Nursing	1	5%
Transport Assistance	5	24%
Other	1	5%
Total	21	

Why haven't you been able to?

No private transport	1	5%
No public transport	1	5%
Don't know where to find out about it	10	48%
Can't afford them	4	19%
Concerned re quality of service	2	10%
Concerned re privacy	1	5%
Other	4	19%
Total	21	

Where do you get info re health?

Hospital	3	14%
CHS	1	5%
GP	21	100%
Specialist	13	62%
Allied Health		0%
Internet	2	10%
Other	3	14%
Total	21	

Where do you get info re home help?

Hospital	2	10%
CHS	6	29%
GP	12	57%
Specialist	7	33%
Allied Health	4	19%
Internet	1	5%
Local Council	8	38%
Other	3	14%
Total	21	

How do you rate the information?

Very Satisfied	8	42%
Satisfied	10	53%
Just OK	1	5%
Dissatisfied	0	0%
Very Dissat	0	0%
Total	19	

How to get Info

Newsletters	15	71%
Brochures	8	38%
Face to Face	10	48%
Internet	3	14%
<u>Presentations at</u>		
Support Groups	8	38%
Written info first visit	2	10%
Written info sub visits	3	14%
Written info to sup groups	8	38%
Other	1	5%
Total	21	

B.2 Survey of 14 people with diabetes.**Age**

0-10	1	7%
11-20	0	0%
21-30	0	0%
31-40	1	7%
41-50	2	14%
51-60	1	7%
61-70	3	21%
71-80	4	28%
81-90	1	7%
91-100	0	0%
Total	13	

Marital Status

Married	8	57%
Single	3	21%
Divorced	1	7%
Widowed	2	14%
De Facto	0	0%
Total	14	

Suburb

Frankston	1	8%
Frankston Nth	1	8%
Crib Point	1	8%
Hastings	1	8%
Mt Martha	1	8%
Cranbourne	2	16%
Seaford	3	20%
McCrae	3	20%
Total	13	

Conditions as well as Diabetes

Anxiety/Depression	3	21%
High Cholesterol	3	21%
Cervical Fusion	1	7%
Osteoarthritis	1	7%
Renal Stent	1	7%
Sleep Apnoea	2	14%
COPD	2	14%
High Blood Pressure	2	14%
Inner Ear Problem	1	7%
Total	14	

How Do You Rate Care Received ?

Very Satisfied	9	72%
Mostly Satisfied	3	24%
Service good but maybe better service	0	0%
Attending as don't know of anything else	1	4%
Actively seek new service	0	0%
Total	13	

Impact on Life

No Impact	5	36%
Small Impact	4	29%
Makes Big Difference	2	14%
Major Impact	3	21%
Total	14	

Other Services Used

Nurse Ed	6	43%
Podiatrist	9	64%
Ophthalmology	3	21%
Dietitian	6	43%
Exercise Classes	3	21%
Dental Services	4	29%
Counselling Services	4	29%
Support Group	2	14%
Rehab Courses	1	7%
Pharmacy	3	21%
Other	2	14%
Total	14	

Activities Unable to Perform

Housework	0	0%
Shopping	0	0%
Gardening	1	7%
Driving	1	7%
Home Maintenance	2	14%
Socialising	2	14%
Community Gps	1	7%
Personal Hygiene	0	0%
Total	8	

What Help or Support would you like?

Nurse Ed	1	7%
Ophthalmology	1	7%
Dietitian	2	14%
Dental Services	1	7%
Counselling Services	1	7%
Support Group	1	7%
Respiratory Nurse	1	7%
Rehab Courses	1	7%
Transport Assistance	1	7%
Other	1	7%
Total	14	

Why haven't you been able to?

No private transport	0	0%
No public transport	1	7%
Don't know where to find out about it	2	14%
Can't afford them	0	0%
Concerned re quality of service	1	7%
Concerned re privacy	1	7%
Other	2	14%
Total	14	

Where do you get info re health?

Hospital	5	36%
CHS	1	7%
GP	10	71%
Specialist	2	14%
Allied Health	0	0%
Internet	3	21%
Other	2	14%
Total	14	

Where do you get info re home help?

Hospital	4	29%
CHS	2	14%
GP	9	64%
Specialist	2	14%
Allied Health	1	7%
Internet	3	21%
Local Council	0	0%
Other	2	14%
Total	14	

How satisfied with info?

Very Satisfied	6	43%
Satisfied	5	36%
Just OK	1	7%
Dissatisfied	0	0%
Very Dissatisfied	0	0%
Total	14	

How to get Info

Newsletters	7	50%
Brochures	5	36%
Face to Face	6	43%
Internet	6	43%
<u>Presentations at</u>		
Support Groups	3	21%
Written info first visit	0	0%
Written info sub visits	4	29%
Written info to sup gps	4	29%
Other	0	0%
Total	14	

B.3 Survey of people with depression/anxiety**Age**

0-10	0	0%
11-20	0	0%
21-30	0	0%
31-40	0	0%
41-50	1	17%
51-60	2	33%
61-70	2	33%
71-80	0	0%
81-90	1	17%
91-100	0	0%
Total	6	

Marital Status

Married	1	17%
Single	3	50%
Divorced	2	33%
Widowed	0	0%
De Facto	0	0%
Total	6	

Suburb

Rosebud	1	14%
Cranbourne	1	14%
Seaford	2	29%
McCrae	1	14%
Rye	1	14%
Dromana	1	14%
Total	7	

Conditions as well as Anxiety/Depression

Diabetes	2	33%
Sleep Apnoea	2	33%
COPD	1	17%
High Blood Pressure	1	17%
Reflux	1	17%
Total	6	

Rate Care Received

Very Satisfied	4	67%
Mostly Satisfied	1	17%
Service good but may services would help me more	0	0%
Attending as don't know of anything else	1	17%
Actively seeking new service	0	0%
Total	6	

Impact on Life

No Impact	1	17%
Small Impact	0	0%
Makes Big Difference	4	67%
Major Impact	1	17%
Total	6	

Other Services Used

Podiatrist	2	33%
Ophthalmology	2	33%
Exercise Classes	1	17%
Dental Services	1	17%
Counselling Services	1	17%
Support Group	1	17%
Pharmacy	2	33%
Other	1	17%
Total	6	

Activities Unable to Perform

Housework	0	0%
Shopping	0	0%
Gardening	1	17%
Driving	0	0%
Home Maintenance	1	17%
Socialising	4	67%
Community Gps	3	50%
Personal Hygiene	0	0%
Total	6	

What Help or Support would you like?

Nurse Ed	0	0%
Podiatrist	0	0%
Ophthalmology	0	0%
Dietitian	1	17%
Exercise Classes	0	0%
Dental Services	0	0%
Counselling Services	2	33%
Support Group	0	0%
Rehab Courses	1	17%
Total	6	

Why haven't you been able to?

No private transport	0	0%
No public transport	0	0%
Don't know where to find out about it	1	17%
Can't afford them	1	17%
Concerned re quality of service	2	33%
Concerned re privacy	1	17%
Other	0	0%
Total	6	

Where do you get info re health?

Hospital	0	0%
CHS	1	17%
GP	5	83%
Specialist	1	17%
Allied Health	0	0%
Internet	3	50%
Other	0	0%
Total	6	

Where do you get info re home help?

Hospital	0	0%
CHS	1	17%
GP	3	50%
Specialist	1	17%
Allied Health	0	0%
Internet	2	33%
Local Council	3	50%
Other	1	17%
Total	6	

Rate Information

Very Satisfied	0	0%
Satisfied	2	40%
Just OK	3	60%
Dissatisfied	0	0%
Very Dissat	0	0%
Total	5	

How to get Info

Newsletters	4	67%
Brochures	4	67%
Face to Face	1	17%
Internet	2	33%
Presentations at		
Support Groups	1	17%
Other	1	17%
Total	6	