

Chronic Conditions

Consumer Journeys Project:

**Rural Consumers'
Experiences
of Chronic
Conditions living
in Portland &
District**





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To inform planning for the Southern Grampians & Glenelg Primary Care Partnership's Integrated Chronic Disease Management activities in Portland & district and Portland District Health's Early Intervention in Chronic Disease initiative funded through the Victorian government's Department of Human Services.

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Acknowledgements:

Participants of the Chronic Conditions Consumer Journey Project

Inner East Primary Care Partnership Victoria

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Portland & District Chronic Disease Management Network including representatives of Portland District Health, Glenelg Outreach, Heywood Rural Health, Glenelg Shire, Winda Mara Aboriginal Corporation, Otway Division of General Practice, DWEC-Aboriginal Elderly Citizens, Lyndoch, Aspire, Community Connections and the Dartmoor Bush Nursing Service

Photo on cover courtesy of Glenelg Shire Council

1. EXECUTIVE SUMMARY

The Southern Grampians & Glenelg Primary Care Partnership (SGG PCP), specifically members of the Portland & District Chronic Disease Management (CDM) Network undertook to investigate the experiences of people living with chronic conditions in Portland and district, including Heywood, in the South West of Victoria. The purpose of the project was to inform the numerous activities in the region which aim to improve the quality of service delivery and coordination of care for people living with chronic conditions.

The Project brief acknowledges that "...genuine partnership between patients, consumers and healthcare providers is important so that everyone achieves the best possible outcomes." (Australian Commission on Safety and Quality in Health Care, *The Australian Charter of Healthcare Rights*, 2008). It also acknowledges that 23 participants cannot represent the views of all of those living within the community, however, as a piece of qualitative research, the project assists service providers to gain some insight into the consumer experience of living with a chronic condition.

It was agreed by the Network that for the purposes of the project, recency or duration of diagnosis of participants would be disregarded and would include the following chronic conditions: Arthritis, Diabetes, Chronic Lung Conditions, Heart Disease and Asthma or other, and would include also carers of people with chronic conditions in this rural region.

The interviews and focus group were structured around eleven open and closed ended questions based upon the methodology of the Inner East PCP Consumer Journeys Project (*July 2007*).

All 23 participants, including 3 carers, were deidentified; a quantitative and qualitative approach with thematic analysis was undertaken.

The participants expressed general satisfaction with the overall service system including coordination and communication between services. However, there were a number of recurrent issues identified by participants including medication access, travel, equitable access to specialist doctors and nurses, patients "dropping out of the system", attending appointments, complaints systems, clear information and care pathways, discharge planning of rural people from metropolitan health services, and other issues such as equipment to enhance rehabilitation, concern for Portland District Health Accident & Emergency (A&E) Department staffing and GP hospital visiting rights.

Participants made many recommendations about how their experience of living with chronic conditions in Portland and district could be improved. Recommendations have been grouped under a number of themes:

1. Enhance access and supply of medications through Community Pharmacies
2. Continue to enhance local access to specialist medical and nursing staff (including use of technology supported consultations)
3. Enhance access to Self Management Support Services through GP and Pharmacist engagement strategies by CDM Network
4. Revise the State Wide Transport & Accommodation Policies for Rural people
5. Invest in Upgrading Local Resources & Infrastructure for Rehabilitation Services
6. Implement 'Early Mental Health Screening for People with Chronic Conditions' Policy ensuring Health Professional referral where appropriate
7. Enhance Communication, Recall and Follow Up Systems in both Metropolitan and Rural Health Services including a robust complaints policy



8. Enhance public awareness of service provision pathways between rural and metropolitan health services as part of support service provision for people with chronic conditions and families
9. Continue to enhance the Emergency Department Service at Portland District Health (PDH)
10. Promote Community Awareness of PDH Policy for GP Visiting Rights for Inpatients

The Portland & District CDM Network Consumer Journeys' Initiative has been a valuable continuous quality improvement process. Consumer participation 'value adds' to strategies and programs being undertaken across the SGG PCP catchment. Recommendations will be communicated back through the Executive of member agencies of the CDM Network for consideration. The report from the Consumer Journeys Project, once endorsed by the Network, will be made available to the participants and on the PCP website.

2. BACKGROUND, AIM & DEFINITIONS

The burden of chronic disease is reported by Department of Human Services (DHS), Victoria as increasing rapidly, contributing to approximately 70% of diseases across six main groups: cancers, cardiovascular disease, injuries, mental health conditions, diabetes and asthma.¹

SGG PCP, specifically members of the Portland & District CDM Network, undertook to investigate the experiences of people living with chronic conditions in Portland and district, including Heywood, in the South West of Victoria in order to inform the numerous activities in the region which aim to improve the quality of service delivery and coordination of care for people living with chronic conditions.

The Project brief acknowledges that "...genuine partnership between patients, consumers and healthcare providers is important so that everyone achieves the best possible outcomes." (Australian Commission on Safety and Quality in Health Care, *The Australian Charter of Healthcare Rights*, 2008). It also acknowledges that 23 people with chronic disease cannot represent the views of all of those living within the community, however, as a piece of qualitative research, the project assists service providers to gain some insight into the consumer experience of living with a chronic condition.

A "chronic medical condition" is defined by the Medical Benefits Scheme (MBS) as '...one that has been or is likely to be present for at least six months, including but not limited to asthma, cancer, cardiovascular illness, diabetes mellitus, musculoskeletal conditions and stroke.'² However, it was agreed by the Portland & District CDM Network that for the purposes of the project recency, or duration of diagnosis would be disregarded and would include the following conditions: Arthritis, Diabetes, Chronic Lung Conditions, Heart Disease and Asthma or Other, and would include carers of people with chronic conditions in this rural region.

3. OBJECTIVES

The SGG PCP sought in-depth information from people living with chronic conditions in Portland and district about:

- The service provision pathways provided by both rural and metropolitan based services for people with Chronic Conditions living in the Glenelg Shire;
- The experience of living with a chronic condition(s) in a rural setting;

1 (DHS Vic Primary Health Branch, CDM guidelines, October 2008, p3).

2 (Department of Health & Ageing website: 6/01/09;Enhanced Primary Care Program, Chronic Disease Management Item Explanatory Guidelines www.health.gov.au/internet/main/publishing/.nsf)

- Consumers' expectations of the health and local government services that they access;
- Glenelg Shire, neighbouring and metropolitan health services performance in providing services for people and their carers/families with chronic conditions;
- Services accessed;
- Service gaps; and
- Improvements recommended.

4. PROJECT METHODOLOGY

A proposal for the Consumer Journeys project was presented to the PCP member agencies to consider, including the 'Participant Information and Consent Form' (SGG PCP October 2008), and it was endorsed by all member agencies' necessary processes in November 2008. The CDM Network members agreed to present the final report of the project to their organisations' Executive groups.

Participants were recruited via a media release in the local newspaper, flyers and posters disseminated to waiting rooms, GP Clinics and pharmacies in Portland and Heywood and to all members of the CDM Network. During November and December 2008 members of the CDM Network agreed to refer participants to the project. CDM Network members referred people with chronic disease to the project using the DHS Service Coordination Tool – 'Initial Needs Identification' and 'Consent to share details' forms.

Participants were reimbursed according to the SGG PCP Consumers Reimbursement Policy (2006) including a travel allowance with an added gift voucher for the participants' local pharmacy of \$25.

One focus group was held in Portland and 16 individual interviews conducted at either the participant's home or at the PDH Community Health Centre. The interviews and focus group took between 30 and 90 minutes.

The interviews and focus group were structured around eleven open and closed ended questions based upon the methodology of the Inner East PCP Consumer Journeys Project (July 2007).

The participants

- (i) Total no. referrals received: 29
- (ii) Total no. consented participants: 23 with chronic condition (includes 3 carers)
 - Female: 6
 - Male: 17
- (iii) Place of Residence: Portland (19)
 - Heywood (4)
- (iv) Age of Participants with Chronic Condition: 24 – 86 years (Mean Av. Age: 50 years)
- (v) Chronic Condition(s) experienced by consumers:
 - Diabetes Mellitus -Type 2 (10)
 - Cardiovascular Disease (9)
 - Chronic Airways Disease/Asthma (2)
 - Arthritis (2)
 - Depression/Anxiety (2)



- Stroke (2)
- Parkinson's (2)
- Prostate Cancer (2)
- Chronic back injury (2)
- Other: Fibromyalgia (1); Autism (1), Epilepsy (1), Bipolar Affective Disorder (1), Polycythemia Rubavera (1) Chronic Renal Failure (1),

(vi) Duration of Chronic Condition: 6 months – 40 years (Mean Av. Duration: 12 years for living with a Chronic Condition)

Note: One Family interviewed with three (3) members living with a chronic condition, including the primary carer.

All participants were de-identified; a quantitative and qualitative approach with thematic analysis was undertaken. All participants will receive a copy of this report upon endorsement from the CDM Network and the report will be made available to DHS Victoria and will be posted on the SGG PCP website.

5. SUMMARY OF KEY ISSUES

The participants expressed general satisfaction with the overall service system including coordination and communication between services. However, there were a number of recurrent issues identified across participants as outlined below.

- **Medication access** to brand of choice and supply issues from the community pharmacies of Portland; experiences of depleted supply of common medications such as insulin; and, a perception by participants of local pharmacists' influence over them to exchange a brand name medication for the generic branded product. Participants, although not representative of the whole community, reported dissatisfaction with generic branded products.
- **Travel** to metropolitan or regional health services and reimbursement policy. The cost and logistics of travel to Melbourne, Geelong and Ballarat, including not knowing how to find appropriate accommodation were reported as an issue. The process of completing the forms, including who can verify the application, for reimbursement through the Victorian Patient Transport Assistance Scheme (VPTAS), was reported to be very demanding, particularly for those who are elderly, have eyesight, cognitive or literacy anomalies.
- **Equitable access to Specialist Doctors/Nurses.** The need to continue efforts to attract specialists to Portland so as to avoid the necessity to travel was commonly expressed.
- **Dropping out of the system.** Participants reported 'dropping out of the system' or not accessing health services or support for extended periods of time during their illness for a variety of reasons including: lack of knowledge regarding their cycle of care or lack of knowledge in changes in treatment modalities over time, perceived difficulty to access services, feeling "self sufficient" in regards to self management and general feeling of "wellness" at present time. Participants reported wanting their Health Professional to be aware of the variety of mediums they will choose to gain their knowledge and support from, such as the internet, and wanting support to find reliable sources of information and support outside the health service.
- **Attending appointments** can become "a fulltime occupation" for people with chronic conditions. Means for supporting them to attend appointments as part of a recall system, asking them for example: text, email, hardcopy letter or phone call reminder to attend appointments would be appreciated and beneficial, particularly when the number of disciplines they are referred to are comprehensive.

- **Complaints systems** – how consumer complaints are processed. Participants expressed frustration and disappointment that either written or verbal feedback of outcomes is not provided by (frontline) managers from a small number of deidentified services – metropolitan and rural based.
- **Clear information/Care Pathways** and communication systems are required between rural and metropolitan health services to decrease stress for clients/carers in emergency/urgent medical conditions from admission to discharge. The question was raised by a carer of how do people with cardiac conditions get “selected” (“triaged”) to be transferred to Melbourne, Ballarat and/or Geelong for such cardiac procedures as angiography and stents from the South West District and/or are discharged back for ongoing management and rehabilitation; Main hospitals accessed need to be identified and pathways of care (“Health Service Maps” for Consumers) was suggested to be established with consumer/carer input to assist future rural consumers as they enter the system, typically under emergency/urgent and stressful situations.
- **Discharge planning of rural people from metropolitan services;** The difference in attention to detail and support to return home in comparison to travel/transfer to the service was identified as a major issue; enhancing communication through a liaison person in the metropolitan hospital was suggested for metropolitan health services so consumers and their families had a point of contact.
- **Equipment to enhance rehabilitation;** A purpose built hydrotherapy pool (2) and upgrade Cardiac/Community Rehabilitation facilities and equipment (2) such the treadmills and bike(s) was suggested for Portland and surrounding communities to assist convalescence and optimise health and prevent acute hospital admissions.
- **Concern for PDH A&E Department staffing** by doctors and continuity of care by nurses within the Department when nurses were rotated through from other units (2);
- Concern expressed over the rationale behind the PDH policy regarding some participants’ **General Practitioner visiting rights** and how this differs to admitting rights of doctors at PDH (3).

6. SERVICES ACCESSED BY PEOPLE WITH CHRONIC CONDITIONS:

Services and location of the services accessed by participants with chronic conditions across twenty two (22) providers were identified as follows:

- General Practitioner – 100% (23) – 4 participants reporting completion + benefit GPMP (GP Management Plan) and TCAs (Team Care Arrangements) to their self management including cost, equitable access, knowledge of services and contact numbers to access support services
- Pharmacist – 100% reported having Pharmacist Services but specific education (Cardiac Rehab – 10, Home Medication Review – 3, 2 at counter education 1:1; blister pack service – 1)
- Pathology – 100% service reported

Allied Health:

- Dietitian – 16 (Portland, Heywood)
- Physiotherapy – 12 (Portland, Heywood, Melbourne, Geelong)
- Podiatry – 11 (Portland Public, Heywood Private)
- Occupational Therapy- 9 (Portland, Heywood, Melbourne, Geelong)
- Social Worker – 7 (Portland, Melbourne, Geelong)



- Psychologist – 4 (Portland Public, Private)
- Credentialed Diabetes Educator – 5 (Portland)
- Counsellor – 4 (Portland, Warrnambool)
- Speech Pathology – 1 (Portland)
- Medical Specialists: Visiting Specialists to PDH, or Travel – Warrnambool, Hamilton, Geelong & Melbourne
- Cardiac – 10 – (Geelong, Melbourne)
- Ophthalmologist – 4 (Warrnambool, Mt. Gambier)
- Endocrinologist – 3
- Physician – 3 (Portland & Hamilton)
- Neurologist – 2 (Melbourne)
- Respiratory Physician – 2 (Melbourne, Hamilton)
- Rheumatologist – 2 (Melbourne)
- Haematologist – 2 (Melbourne, Adelaide)
- Nephrologists – 1 (Geelong)
- Cardiac Rehab – 10
- District Nursing Service – 6 (PDH, HRH and Port Fairy)
- Community Health – 4
- Hospitals – Admissions – Some individuals went to up to 3 hospitals to receive treatment for one event, typically acute episode – i.e. PDH, Melbourne, Geelong, Hamilton locations

Other:

- Paramedics – 10
- Dept of Veterans Affairs (DVA) – 4 (Portland, Heywood)
- Lyndoch – CAPS Package – Case Manager – 3 (Portland)
- Local Government Services – 3 (Heywood)
- Respite – 3 (Portland, Heywood)
- Dental – 3 (Portland)
- Optometrist – 2 (Portland private)
- Psych Services – 1 (Portland)
- Radiology – 1 (Portland)
- Drugs & Poisons Unit – 1 (Portland)
- State Government Services – Victorian Civil & Administrative Tribunal (VCAT) – 1 (Portland)
- YMCA Rehab – 1 (Portland)

Alternative Therapies:

- Osteopath – 1 (Portland)
- Chiropractor – 1 (Portland)

7. THE PATHWAYS THROUGH SERVICES FOR PEOPLE WITH CHRONIC CONDITIONS & SERVICE PERFORMANCE

A majority of participants rated the smoothness of their transition from one service to another, as 'adequate' and that they were generally 'satisfied' with their experience of point of entry describing the transition between health services from Portland District Health and/or Heywood Rural Health to larger

health services in Hamilton, Warrnambool, Geelong and Melbourne as generally 'smooth'.

There were, however, a number of descriptions by consumers of 'needs a lot of improvement' based on miscommunication or lack of communication, issues experienced by the family and/or carer of a person living with a chronic condition(s) particularly when placed under duress or when facing a new situation resulting in them describing a lack of 'self efficiency' due to the confinements of the underpinning support service.

The following four case studies are journeys told by participants who stated that they recognise the need to address issues pertaining to the underlying service system that supports clinical management. For the purpose of this project all four case studies (including background detail) have been verified prior to publishing. They include the following themes:

- Communication and discharge planning including support for travel for consumers back from metropolitan health services having once received care
- Effective communication and provision of feedback to clients and carers from Managers/Team Leaders in response to consumer complaints
- Continuous Quality Improvement of systems management: input and responsiveness of both clinicians and managers of health care services
- Transport and accommodation for rural Victorians and the rate of reimbursement

Consumer A's story:

"They [PDH] put so much effort in getting you transferred to a Melbourne Hospital but not much effort is applied to getting you home again. My son drove himself and my wife to Werribee. Because neither of them are confident at driving and navigating their way around Melbourne they caught the train in and then I caught a taxi back with them to Werribee and then they drove me home after my heart attack. I felt like I had been put out on the street with not much consideration as to what next."

Consumer B's story:

Background: A Carer reported on his experience of miscommunication between the appointed care assessor, the family and his elderly father. The care assessor did not meet with the family as prearranged. As a result the carer reports his father misinterpreted that he was going to be admitted to residential care full time rather than for respite. The family lodged a complaint through their local health services Management regarding the particular visiting service because "...as a result [to action of care assessor] dad thought we were going to force him into residential care. It really affected our relationship with him. Things from the past, painful things that we thought we had dealt with resurfaced. And poor mum ...we wanted the opportunity to first let the worker know about our family's background. This was made worse with the time delay prior to seeing us, dad became really upset..."

A Senior Medical Clinician was appointed to respond to the next of kin (brother and sister) following receiving the letter of complaint. The son (power of medical attorney) responded that they (the family) gratefully received a substantial amount of time with the clinician, explaining and addressing the issues with them. However, the carers still have not received a letter or phone call from the Manager of the service in response to this issue, claiming that despite the clinicians visit they would appreciate feedback or an apology in response to their complaint in acknowledgement that "...our complaint had been heard and that steps to avoid this situation from being repeated was being taken but it seems that it remains open to us."





Consumer C's story:

Background: This consumer tells her journey as the next of kin and wife of a husband who consequently died of cardiac condition two years earlier. The woman commences her story, voicing that she is aware of "...the right to privacy and confidentiality" but shares her frustration of not being made more aware of the care pathway her husband would take transferring from their local GP to a larger rural hospital and then onto a metropolitan health service.

"When my husband was discharged, he told me of his discharge instructions from the particular health service. What was his discharge plan post angiogram? I was not informed and he was discharged out the door with nothing written except being told that he would be admitted for a stent in four weeks when the service would contact him by phone... he was discharged before I had the opportunity to ask any questions. I received little feedback from our GP (who afterwards when I spoke to him, said that GP's, once the patient has been referred on to the specialist was left in their care unless otherwise instructed), and the specialist he referred my husband onto; I received reassurance from the nursing staff at the ICU (at a larger rural health service) however, after that I received no feedback post angiogram at the metropolitan hospital he was referred onto again for further investigations. My husband had private health cover but was discharged after the angiogram and, as I understand, went onto a waiting list – I don't know why that occurred ...what is the policy at this hospital? My husband following discharge from his angiogram told me that he had 80% arterial blockage and needed a stent in his heart. Apparently this was not considered urgent even though both parents had died of heart attacks; father at 64 years and mother at 78 years (having had open heart surgery some years previously). I took him home here to Portland but urged him in two weeks to contact our local GP because he was feeling unwell. He made three phone calls in a row at my insistence – first the GP, whom he later consulted, then the specialist at the neighbouring rural hospital and finally he rang the Cardiologist attached to the Catheter Lab at the next health service. As a result, he had the stent procedure brought forward by two weeks, but still was a ten day wait. He died the morning he was to be admitted, at the home of our friends where we were staying in the same town as the metropolitan hospital. I have been advised to write a letter of complaint to the larger hospital ...it has now more than two years from my husband's passing."

She goes on to say: "I went and made an appointment to see the Cardiologist off my own back to try and find out what happened. I told him (the Cardiologist) outright that I did not want to sue; I just wanted to know what happened to my husband... I told him that I was disappointed about the level of communication and the Cardiology Unit at the hospital and this really needed to be improved... he could only say he was sorry. That was nice but I want the system of communication within that particular health service and across health services

and/or specialists and the next of kin or patient to be reviewed so this never is repeated... I was in fact sent a bill for future pending surgery (the stent) from the particular hospital, for surgery my husband never had because he died the morning before it was rescheduled. I know there can be mix ups between admissions and discharges and accounts departments but I think that's poor."

"I also spoke to the specialist of the larger rural hospital, he was shocked at the outcome - had been overseas for some months and was unaware. When I asked why he was referred to that particular metropolitan hospital, where the stent was not likely to be done at the same time if needed, replied that the particular rural hospital he was working at was encouraged to send patients to that particular metropolitan hospital rather than a Melbourne hospital. I asked if this could be reviewed, and he assured me he would look into it. I asked the Cardiologist at the metropolitan hospital if it could be reviewed at that hospital also, and he assured me he too would look into it. I am not aware if anything has changed. I feel I, and my family, have been let down by our hospital/health system."

Consumer D's story:

Background: This carer also is living with a chronic condition; she cares for her husband and son who also live with a chronic condition. She tells of the tyranny of distance particularly including when her son needs to see a Neurologist in Melbourne (to enable him to receive his epilepsy medication script on authority) and the financial concerns for her family as a consequence.

"I would like to see changes to the Victorian Patient Transport Assistance Scheme (VPTAS) to help my family attend our specialists, as our family has three members with chronic conditions and we are pensioners. The scheme only supports you if you live 100 kilometres from the point of appointment. As we live on this side of town, if we attend an appointment in Warrnambool we can be 3 kilometres short of qualifying for the reimbursement of fuel of 17 cents per kilometre. With fuel costs in the country more expensive, even though fuel overall is decreasing, it still costs country people more to fill the car than those who live in Melbourne not to mention the wear and tear on your vehicle...We have clocked up close to 2000 kilometres in less than 6 weeks! This was because I took my son and then my husband down for individual appointments with their specialists. I try and get the appointments at the same time, this is not easy to organise, and we have found accommodation for \$30 a night in a hostel... I moved from Melbourne many years ago to Portland and I worked in Melbourne so I am lucky I can drive in Melbourne and of course I am the sole driver."

There are five (5) detailed examples of pathways taken by participants that are included in the Appendix 1.

The common themes in these pathways are:

- GPs (and Practice Nurses) are pivotal in coordination of care and initiation of multidisciplinary service provision
- Pathways are influenced by the point of contact & consumer journey complexity (Consumer D)
- Opportunities for re-engaging a client with a chronic condition can be an oversight for example, hospital admission for another acute condition or procedure (Consumers C and D)
- Over time, there can be cessation in the relationship between consumers and their chronic disease support services without due planning, that if this does occur, as to how to re-engage (Consumers C and D)
- The necessity of consumers who live in rural areas to travel to various sites- metro, larger rural health services in addition to local acute, allied health and primary care services to access appropriate levels of care, further add to the complexity of consumers' experience living with chronic condition(s) (Example E), and
- Self management of chronic conditions in the rural setting due to the above themes may itself add to individual's personal cost and stress,

detracting from their ability to self manage their condition and contribute to their decision or “acceptance” to withdraw in part or cease provision of support services for their condition(s) indefinitely (Consumers A and B).

8. THE EXPERIENCE OF LIVING WITH A CHRONIC CONDITION IN THE GLENELG SHIRE

Many participants recounted their personal experiences living with their condition(s) (or caring for someone) revealing common themes whereby they have:

- had to learn to make behaviour changes in order to live with their condition and with this knowledge and consequent experience has resulted in greater self efficacy
- identified financial costs and the incalculable costs of living with a chronic condition such as loss of time with family
- acknowledged the importance of self management support services including support groups and use of information technology and barriers to accessing support services, including IT access, necessary to achieve goals, make and retain behaviour changes
- identified the value of mental health screening for all people living with a chronic condition
- identified the uncertainty surrounding the future for people living with chronic conditions, and
- experienced some of the frustrations for both people with chronic condition and/or their carers/families when it is the support services underpinning system that detracts from their quality of life.

8.1 Learning to Cope with your Condition through Life Experience & Self Management Education

Participants reported that life experience combined with self management support services, including self management education, assisted them to ‘cope’ more positively with their condition(s).

“You know there are flair ups of the condition (Fibromyalgia) so you know that this is as good as I am going to get today. Flair up means that I have over done it. This occurs in cycles. I’m a realist, so you still have a choice but need to prioritise what you do. For example, bake and go to bed or buy a biscuit and play with your kids!”

“You learn to strategise as a means of daily living to an extent... I often need to have someone with me and therefore need to plan my outings. I learnt this by undertaking a self management course (Better Health Chronic Disease Self Management) – it has taught me to be more self aware of my limits and to be more positive.”

8.2 Financial Cost to the Consumer

The financial burden to the individual and/or carer with a chronic condition needs to be taken into consideration with participants identifying a number of schemes that were of benefit.

“DVA transport allowance is a great support if you do have to travel to see a specialist.”

“The medication I take there is no PBS (Pharmaceutical Benefits Scheme) – it costs approximately \$145 (56 tablets). Then you still have to travel to Melbourne to see the specialist – he looks at my son, says a hello and writes the script. He has the authority only.”

“The NDSS (National Diabetes Services Scheme) helps me to afford to monitor my blood sugars. I am not on a health care card so the cost of

medication is enough and I still have to pay for my blood glucose strips.”

“Transport allowance if under 100 km one way and there is no reimbursement and if under. Also reimbursement for travel to appointments is only 14c per kilometre I think, we are still paying over \$1.30 at the pump in Portland for fuel despite fuel decreases recently. We were paying nearly \$2 at one stage but reimbursement remained the same.”



8.3 Self Management Support Services

The Portland & district community self management support services were overall positively appraised by the participants. Issues identified generally reflected an absence or delay of feedback regarding support service provision from a service to the participant.

“I have also had rapid Bipolar Disorder for 28 years and have had 50 shock treatments, medications until 15 months ago without much success. Until a new medication was tried, I have had only around four episodes since then. The help I have been given by Psychiatric Services has been amazing. I am no longer on their list, but if anything does become a problem I have only to contact them by phone and they will help me. Their service and caring has been wonderful helping me and my family to cope.”

“I never received HACCC (Home and Community Care) services post surgery – I was told I was being referred but they just did not show up – I never received a phone call to feed back why they would not visit me. Meals on Wheels are excellent.”

“I never went to a doctor unless my finger was chopped off or something like that. Until, that was, I had a heart attack... Cardiac Rehabilitation and the nurse have been a great support as well as my local doctor. He follows up test results and rings me on my mobile and gives me instructions what to do (patient illiterate).”

“I want to see a support group for Fibromyalgia set up locally – I know at least five of us with it. I have approached the Community Health Service and am awaiting a response.”

“I don't see the Diabetes Educator as much now; I have had diabetes for 20 years but she has been supportive. The most helpful these days is the Diabetes Support Group – you live with diabetes 24:7 and we have had guest speakers such as the Diabetes Educator, a pharmacist and Dr. Ralph Audem from Diabetes Australia up. But we bring food to share, we meet at Neighbourhood House which is a good venue, and we now have a website up, MG2”.

“As I get older, things happen more quickly. The Parkinson's group and my wife are my greatest supports. When you are diagnosed, Parkinson's is like a big black smoke coming towards you – you don't know what is coming towards you next.”

8.4 Self Management Support Services through use of Information Technology (IT)

Participants of all ages reported that they use the internet to find out information to assist them to self manage their chronic condition, however, not all information is guaranteed: its quality, evidence base and recency. Some consumers reported that they used websites that were recommended by health professionals to them e.g. Diabetes Australia. Barriers to use IT such as the Internet included lack of computer knowledge or the lack of interest if offered the opportunity to learn.

It is anticipated that use of Information Technology Services will increase with the next generation, however; some older people do have computer skills or



express the desire to learn or have easier access to computers.

“I use the internet to research my condition.” (3)

“I use a computer for emailing and the internet but I am not a real fan.”

“I use the internet all the time and email. I also have a mobile phone for calls or text messages.”

“I use the computer for warning me of upcoming appointments, the internet to research our family’s chronic conditions and to access information or support services.”

“My daughter looks up information for me.”

“I would have to go down to the local library to access Internet. I don’t have time to learn how to use it!”

8.5 Mental Health Screening

All (23) participants agreed that people with chronic conditions should receive early mental health screening for detection of depression and anxiety, and other mental health issues.

“How are you supposed to manage your condition if you are too depressed or overly worried by either your condition or something else going on in your life? Yes by all means.”

“We had screening done when we first went to cardiac rehabilitation, no big deal. I have been seeing a psychologist at the community health centre for a while now.”

“My GP has now also put me on antidepressants for my depression and I feel like a different person.”

9. CONSUMER EXPECTATIONS

Participants reported that they expected to be informed of resources to assist them to self manage their chronic condition, how to access support groups and opportunities to enhance social connectedness, and to be provided with timely and equitable access to specialists and support services, avoiding the need and cost to travel where possible.

Recommendations for improving the health service for people and their families living with chronic condition(s) in response to their expectations include:

9.1 Communication & Management Plan between You (your family), Your GP & Chronic Disease Support Services

(i) A positive relationship with your local GP (8):

“Good communication is the key. My GP and I are kept in the loop by the Heart Specialist and Ophthalmologist in Warrnambool. A pharmacist that can visit you to explain how medication changes, the PBS, access and products. Also access to a podiatrist.”

“A good and supportive GP.”

“Regular review by my GP – every 6-8 weeks suits me. Also having a GP Management Plan completed – it has all the phone numbers of people I may need to contact for further information or in an emergency. I travel interstate over the winter months so I carry a copy of this plan with me.”

“Development of a GP Care Plan (GPMP + TCAs) – it tells you who to contact, when and how.”

“Having telephone access to your GP or care coordinator”

“PDH need to address the doctor roster for the Emergency Department.”

“Admitting rights of GPs – PDH need to be addressed. I find it frustrating that my GP does not have visiting rights.”

(ii) Access to a variety of self-management support services:

“Access to a rehabilitation program (including Cardiac Rehabilitation – with access to a Dietitian and Pharmacist)” (5)

“District Nursing is another essential service.”(4)

“A supportive partner” (2)

“Regular access to services such as a Podiatrist which I see monthly, access to a Dietitian and Diabetes Educator. I had one to one meetings with them all when I was first diagnosed three years ago.”

“Having access to local services for rehabilitation and physiotherapy... not having to travel and for ongoing support.”

“Also being linked into a support group who can tell you about what is available to assist you. ”

“Discharge planning, in particular transport home, is also important. “

“Access to social supports such as the Day Centre.” (2)

“A dedicated hydrotherapy pool. The so-called heated swimming pool in Portland is not a hydrotherapy pool... (2)

“Disability parking in the appropriate places. Our local council needs to have a serious review of where the current places are positioned.”

“I am under DVA, however, I am not a gold card... It would help if the guy from DVA was given more hours to support us. It is important that you have an advocate to help you to work your way around the system. I have joined the RSL to find support from a group of men of similar background.”

“You need a puffer and a visiting nurse (Asthma Nurse) to teach you the right technique to use it.”

“The Parkinson’s Support Group -initially I did not want to go but over time I have found it valuable. Also trusting your health professionals as part of your care.”

“Regular contact from Psych. Services from my case manager who used to visit me twice a week or phone me. I have been taken off the books but I still have a point of contact if I need to access services which give me reassurance to know that you can ring and reopen or if you relapse... Talking to a Chronic Disease Management Support group has been OK, hearing from people from different backgrounds.”

“Address the waiting list for podiatry services.”

“Ultrasound – waiting time for this service needs review at Portland.”

“Transport – public transport to local and Melbourne hospitals needs to be addressed.”

“Support groups and frequency and local access required assisting in the increased knowledge of Parkinson’s medications by individuals or through a Home Medication Review?”

(iii) Pharmacology knowledge, safe administration of medicines of participants and their carers and availability of medicines:

“It is essential that your medications are delivered on time when admitted to hospital if you have Parkinson’s. There has been lack of understanding of needing your medications at regular times on admission in the past, so much so it has upset my husband. A team meeting addressed the medication issue.”

“I had a pharmacist tell me about Home Medication Reviews – this is an excellent service.”

“Waiting time to access medication through local pharmacists, run out of regularly ordered medication that leaves you with a 2-3 day waiting time, go to other chemist, drive to the Heywood chemist or go to Mt. Gambier are your choices...I have had to drive over to Mt. Gambier (one hour drive) to obtain medication.”

“Generic use of medication is promoted through the local pharmacies. It is not a cost saving measure because we know that my husband’s Parkinson’s becomes unstable when he is given generic or administered medication too late.”

“Generic medication when my doctor says and I know that brand medicine works better. Also running out of medication that I regularly take at the pharmacy is not satisfactory and should be addressed.”

9.2 Avoiding travel /Access to Specialist Doctors

Travel was a common issue raised by participants with a call for continued recruitment of visiting specialists to Portland to assist in addressing this issue.

“Avoidance of having to travel some distance to access services necessary to assist me to manage my own condition”.

“Access to appropriate specialists” e.g. Cardiac Surgeon

“You need access to a Haematologist – this is essential! I had to drive to Adelaide to access one as my doctor up in Noosa said it was urgent that I went and saw one. I rang Adelaide on the Thursday and they got me in on the Tuesday rather than waiting at least a week to see one at Warrnambool.”

“Having access to medical (and nursing) specialists to ensure that referral is made early and timely – this is vital and that access to services is fair and equal to all. Also having access to the right counsellor that has been trained to assist you to look on the positive side and one that suits you.”

“Having access to a Heart Specialist that visits Portland. Cardiac rehabilitation is delivered locally.”

“Address the travel issue and better utilisation of our local facilities – continue to attract specialists travelling to Portland such as an Endocrinologist for my diabetes would make sense.”

“Having to travel is expensive in time and resources and you physically need to be able to travel. More specialty services to Portland and Heywood would be appreciated including an Eye Specialist (Ophthalmologist) – equipment cost apparently a barrier in the past but I know that Bairnsdale has a visiting eye specialist who conducts cataract surgery but not laser therapy. We could just continue to go to Warrnambool for laser.”

“From Portland to Melbourne to access specialist services need to address the transport issues including inconvenience and stress, cost not so much a factor for me.”

9.3 Transport & Accommodation in order to access Specialists & other support services:

Participants reported travel assistance and accommodation advice could be enhanced for rural people.

“Transport to services – when you are in the country we have to often travel to Melbourne (385 kilometres from Portland). I have one specialist that comes over from Warrnambool to Portland which is brilliant.”

“Transport to services – when you are in the country and you have to go to Melbourne. I have a visiting specialist physician from Warrnambool that is great. Timely provision is critical including access to appropriate specialists such as a Cardiac Surgeon.”

“Travel assistance because people in the country have to travel so much to get access to specialist services.”

“Try and coordinate appointments and tests etc. needs to be taken into consideration for country people. Both my husband and son need to go to Melbourne to see their specialists (for their respective conditions). Metro services need to understand the travel we need to do....We can get accommodation for \$30/night at Ivanhoe called ‘Ryder Cheshire’ where as a family we can stay there. I pay up front and can claim accommodation through VPTAS. You need to be aware that a letter from a Registrar will not be satisfactory to support your claim though, you need the Consultant to write the letter or you cannot be reimbursed. This is not explained in the pamphlet.”

“Educate the metro health services about what it is like to live in the country and to access their services. Assign an intake worker (key worker) to guide people entering the health service. “

9.4 Infrastructure and Resources

Participants reported having good access to appropriate infrastructure was helpful in managing their chronic condition.

“Need better updated equipment (Cardiac Rehab) it works but it needs upgrading and there is not enough equipment such as treadmills and bikes.”

“A hydrotherapy pool. The pool here in town is not a hydrotherapy pool for physiotherapy.”

9.5 Effective Communication & Feedback Systems

Effective communication systems included use of hand held records, use of GP care plans with contact numbers, telephone coaching, case management systems and complaints feedback systems. Communication systems were often identified by participants to be of particular importance when visiting metropolitan health services for treatment or when travelling.

“Communication with metropolitan hospitals. I lost my husband once – he just went missing! He was admitted to a metropolitan hospital for elective surgery (a knee replacement) that was consequently cancelled. I was rung and left a message that he was going to be discharged direct from theatre at 8 am. I rang the ward he was originally admitted to, called a Medihotel, to talk to him and tell the staff that I was nearly 400 kms away – this was around 10 am. They said he was not there. I kept ringing the hospital. At 4:30 pm they found him in another ward. I sent a letter of complaint back in early September. It is now two months later and I still have not received a response.”

“Ring us back. I get calls and never hear again from that person or it is days later. The carer needs to ring and avoid chasing people all the time. One central case manager has made a difference to my father...A patient advocate is required. ”

“We travel up north for the winter... I take a list of my medications and my wife knows how to contact my local doctor down here and my Haematologist.”

“Being able to get past the receptionist or to have something on your history that tells the receptionist that you are not to be mucked around with and need an early appointment or otherwise you probably will end up being admitted to hospital.”

“Phone access for (ambulatory) insulin adjustment at home.”

“Cardiac cards need to be updated. The card/booklet you carry needs to include your latest medications but not be too big. Recommend that you carry one especially if you travel.”

“Encourage use of the calendar on computers or some other reminder system for alerting people of their appointments and making new appointments. I had 22 appointments in a month once including GP, eye doctor, renal specialist, podiatrist and district nursing.”



“When you are admitted to hospital are you not automatically referred to a Diabetes Educator? Surgery does affect my blood sugars.”

“Recommend that health services review their policy regarding assessment of clients and family and their communication strategy. Complaints made warrant feedback – even a phone call from the Manager ...to acknowledge that they hear what you have to say!”

“How is it decided, what is the policy, as to where patients are sent from our rural areas – sent to Ballarat, Geelong or Melbourne? I believe that this need’s to be addressed. ...I just want the system reviewed so this does not happen to anyone else.”

10. CHRONIC CONDITIONS GAPS

The results demonstrate that not all the participants living with a chronic condition are accessing support services according to best practice guidelines. Of the ten participants living with diabetes for example, only half (5) reported that they received service support from a Credentialed Diabetes Educator; however, the General Practitioners were reported by the participants to be supporting those in 100% of cases. A high proportion of participants also reported having seen a Dietitian (16) however, not all people with diabetes had been referred to see a Dietitian by either their GP or other health professional.

Participants reported they had attended support services early on in their diagnosis however, over time had ‘dropped out’ of the system for various reasons such as concomitant illness, no recall system to re-enter support service provision or no knowledge of the importance or motivation to re-enter the health system for ongoing support and management of their chronic condition.

These findings emphasise the need to address interagency and cross agency assessment and care planning, patient/client recall and patient feedback systems for GPs, Allied Health Units and Primary Care and linking these systems with allied health in the private sector including podiatry, physiotherapy, optometry, dental, psychology and ophthalmology services so individuals do not ‘drop out’. It is also suggested that through this type of system reform, ‘Decision Support’³ is warranted. This includes the ongoing promotion of ‘best practice’ guidelines for GPs and Allied Health Professionals, enhancing consumer self-efficacy through individual and group education including what is expected as part of their ‘cycle of care’ for their particular condition(s) and from their self management support service.

11. IMPROVEMENTS RECOMMENDED & CONCLUSION

Recommendations for actions to improve health services for people and their families living with chronic condition(s) are:

Recommendation 1

“There seems to be a push on generic medication when my doctors specify brand medication. Also supply – the pharmacies run out of things like insulin – I am taking basic types – Lantus and Novorapid and it concerns me when they say they have run out and they will try and get it in the next day. These issues need to be addressed.”

Recommendation 1: Enhance Access & Supply of Medications through Community Pharmacies to ensure continuous supply of medications including specific brands

Medication supply, participant perception regarding the use of generic medications, and waiting times to access “regularly required” medications is an issue for people living in Portland.

Recommendation 2: Continue to enhance access to specialist medical and nursing staff (including use of technology supported consultations)

The participants recommended continued work in promoting recruitment of specialist medical and nursing specialists to the area, including support

³ (DHS Vic Primary Health Branch, October 2008, p14)

of access to rural and remote health professionals from regional and metropolitan services via modern electronic and telephonic technologies. Opportunity exists for funding telemedicine/videoconferencing facilities to enhance communication.

Recommendation 3: Enhance access to Self Management Support Services through GP and Pharmacist engagement strategies by CDM Network

Participants reported accessing a range of support services through a variety of avenues beyond their local GP or health care worker including the internet and support groups. However, 100% of participants reported having a GP and a Pharmacist demonstrating that these two disciplines are pivotal as self management support services and/or generating referrals to other members of the multidisciplinary team with the participants.

Self Management Support Services can include individual health reviews with health professionals, and implementation of group education programs such as the Stanford '*Chronic Disease Better Self Management Program*'; the provision of support/knowledge and opportunities to enhance social connectedness of rural people living with conditions. Consumers living in rural areas have the right to access equal services however the means to achieve this may need to be undertaken in a different way.

Recommendation 4: Revise Transport & Accommodation Policies for Rural people

The Health Issues Centre (Sept 2008) Melbourne was recently commissioned by the DHS Victoria – Quality Branch to develop a discussion paper about the needs of rural consumers who travel to Melbourne hospitals following concerns expressed by several metropolitan hospitals' Community Advisory Committees (CAC) about the range of issues faced by rural consumers. The study's reference group includes representation from other key bodies including Australian Institute for Primary Care, Statewide Quality Branch in addition to rural acute health services, rural Division of General Practice and consumers.

The HIC argues that the issue of rural consumers using metropolitan hospitals is clearly complex and of a significant scale, especially when seen from the perspective of rural and remote Victorians. They found that nearly 50,000 rural Victorians each year travel to Melbourne for treatment and more than 45% of rural health consumers will use Metropolitan services at some time in their lives. Many other rural and remote Victorians will also use regional hospitals – many of which will also be far from their place of residency. As found in this Consumers' Journey Project, the HIC in the Loddon Mallee Consumers Journey also found that the necessity to travel to obtain services, few do so out of choice; rather, from necessity in order to access the services they require.⁴

Recommendation 5: Invest in Upgrading Local Resources & Infrastructure for Rehabilitation

The results demonstrate that Physiotherapy is the second highest utilised Allied Health Service behind Dietetics, and with the advent of new funding demands generated from projects such as *Early Intervention for Chronic Disease* (EliCD) on Allied Health Services overall including outreach of services across the Glenelg Shire from PDH.

Recommendation 2

"I drive my son to see a Neurologist in Melbourne every three months to enable to get his medication on PBS. The Neurologist knows him, he greets him, asks him questions (assessment) and then he writes him a script... there must be an easier way that would also take the stress out of me trying to coordinate my husband's Rheumatologist appointment with my son's and driving them to Melbourne."

Recommendation 3

"Consider establishing a Chronic Pain Support Group and/or Carer's Support Group like there is in Hamilton."

Recommendation 4

"We need more community transport facilities otherwise – only one Red Cross car and one Community Health Car."

Recommendation 5

"The local pool is not hot enough to provide hydrotherapy for my Rheumatoid Arthritis – we need a dedicated hydrotherapy pool. I stopped going for treatment because the pool was too cold."

4 Health Issues Centre, 2008, p60

5 SANE & DA, 2008, p8

6 NSMHW, ABS, 1998, cited DHS Primary Health Branch, Oct 2008, p35

Recommendation 6

"Mental health screening should be conducted early for people with a chronic condition(s). In the army I did basic first aid but not mental first aid."

Recommendation 7

"The Geelong Hospital Card. I carry it in my wallet. It has my UR, personal details, contact person. On the reverse my GP and his contact no. What Cardiac Surgery I have had and the date, whether I am on blood thinners (anticoagulant therapy) and my blood group."

Recommendation 8

"What is the policy at this hospital? My husband following discharge from his angiogram was instructed to contact our local GP because he was feeling unwell. He made three phone calls in a row at my insistence— first the GP, then the specialist at the neighbouring rural hospital and finally he rang the Cardiologist attached to the Catheter Lab at the next health service in search of assistance. As a result, he had the stent procedure bought forward by two weeks..."

Recommendation 9

"Avoid rotating nurses through the A&E Department who are not familiar with the systems or the position. We need to staff a 24 hour department with doctors and nurses."

Recommendation 10

"I just lost my son to cancer – I would like my own GP to have visiting rights even if he is in Heywood."

Recommendation 6: Implement 'Early Mental Health Screening for People with Chronic Conditions' Policy ensuring Health Professional referral where appropriate

The results suggest that although a small number of consumers participated in the project, just under one third of them (8) had, or are still seeing either a Psychologist (4) or Counsellor (4). This would concur with research that suggests for example, diabetes doubles the risk of depression compared to those without diabetes. The chance of developing depression also increases if diabetes complications worsen.⁵ People with chronic medical diseases commonly experience depression and anxiety. The National Survey on Mental Health and Wellbeing⁶ and the *Victorian Burden of Disease* data supports this conclusion. MBS items also exist for GPs to refer people with mental health conditions for appropriate counseling. The Early Intervention in Chronic Disease (EliCD) Projects for PDH & the SGG PCP have endorsed this strategy.

Recommendation 7: Enhance Communication, Recall & Follow up Systems in both Metropolitan and Rural Health Services including robust complaints system

Participants made various suggestions of how they thought or identified 'what had worked for them' in their experience. The issues identified by participants in support of this recommendation were two fold: it was generally accepted that support for them to attend appointments with their support services would be helpful; and, according to the participant pathways (see appendix 1) there are opportunities omitted in the acute care setting (both metropolitan and rural) whereby people with chronic conditions could have been referred back into the system for example, consumers C & D.

Recommendation 8: Enhance public awareness of service provision pathways between rural and metropolitan health services as part of support service provision for people with chronic conditions and their families

Decision support pathways for participants were not always clear.

Recommendation 9: Continue to Enhance the Emergency Department Service at PDH

Although only two participants raised the PDH Accident & Emergency Department staffing as an issue the author has included the comments for consideration. This issue has been raised by the PDH Board at Portland & District Community Meetings over recent years and will be continued to be addressed as part of continuing quality improvement processes.

Recommendation 10: Promote Community Awareness of PDH Policy for GP Visiting Rights

Three participants raised the issue of not being aware of the PDH Policy for GP visiting rights with their comments for consideration as part continuous quality improvement.

Conclusion

The Portland & District CDM Network Consumer Journeys' Initiative has been a valuable continuous quality improvement process. Consumer participation 'value adds' to strategies and programs being undertaken across the SGG PCP. Recommendations will be communicated back through Executive of member agencies of the CDM Network for consideration. The report from the Consumer Journeys' Project, once endorsed by the Network, will be made available to the participants and on the PCP website at www.sggpcp.com/chronicdisease/index.htm.

12. REFERENCES

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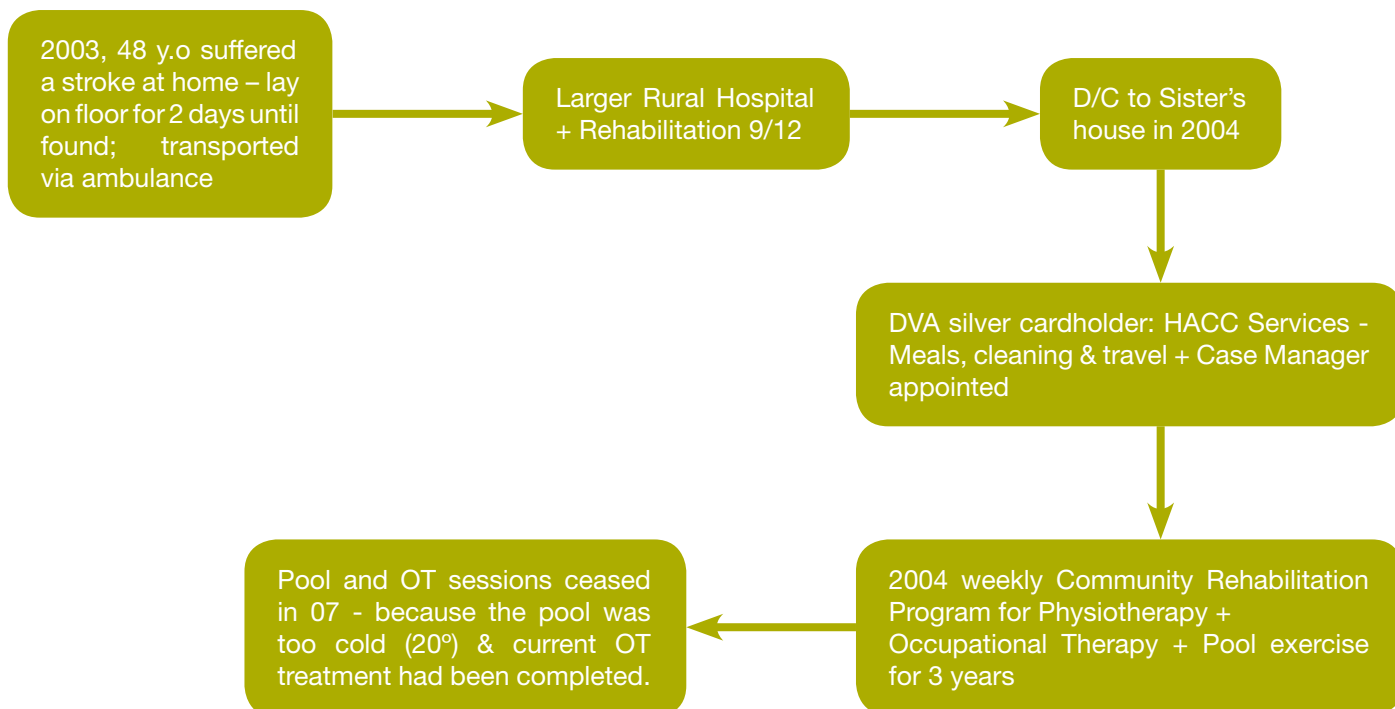
Inner East Primary Care Partnership (July 2007) '*Consumer Experience of Diabetes Services – Qualitative Research*' pp 1-15

SANE Australia & Diabetes Australia (2008) '*The SANE Guide to Good Mental Health for people affected by diabetes*', www.sane.org p8

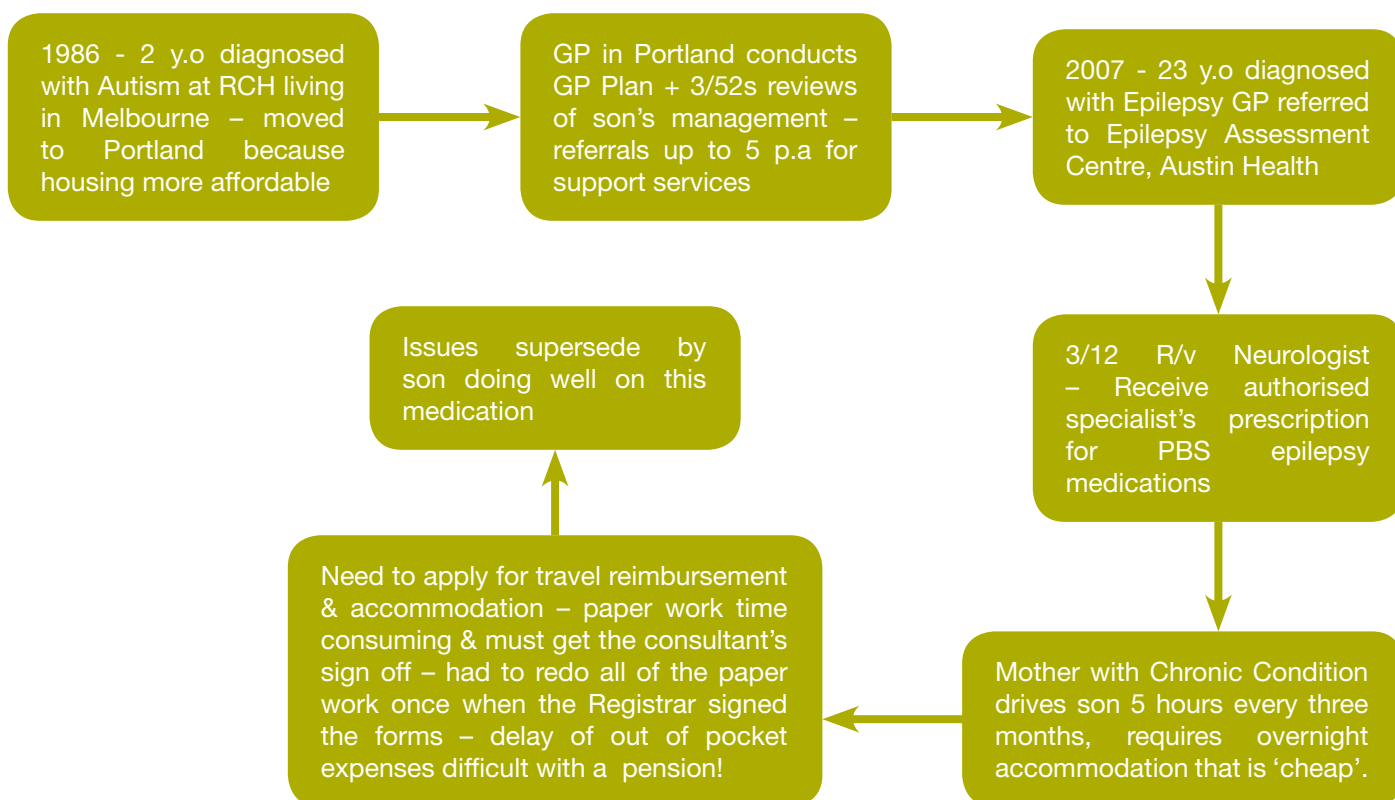
National Survey on Mental Health and Wellbeing, ABS, 1998, cited DHS Primary Health Branch, Oct 2008, p35

APPENDIX ONE: PATHWAY EXAMPLES

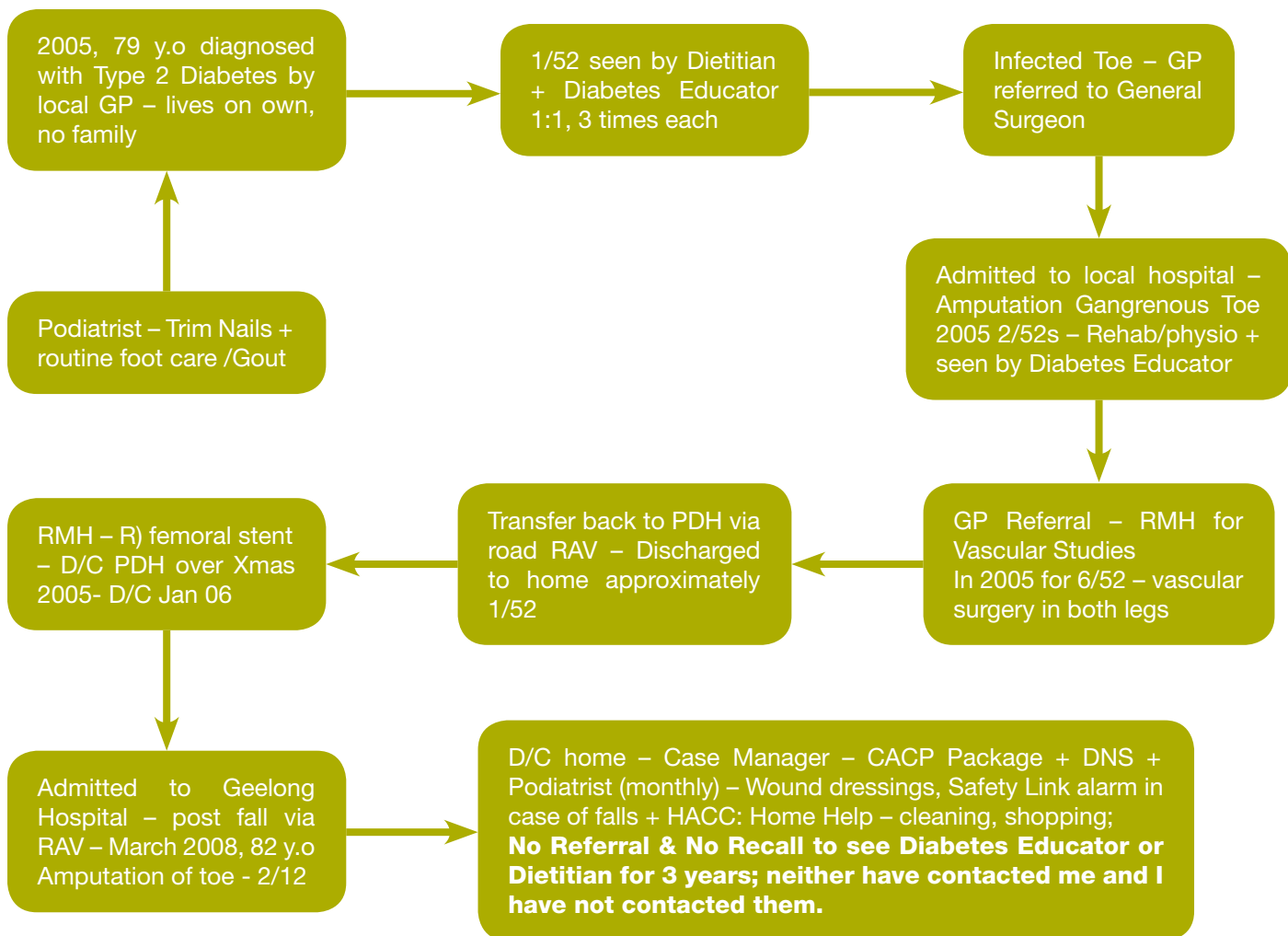
Consumer A: "No Feedback or consultation as to why services are ceased".



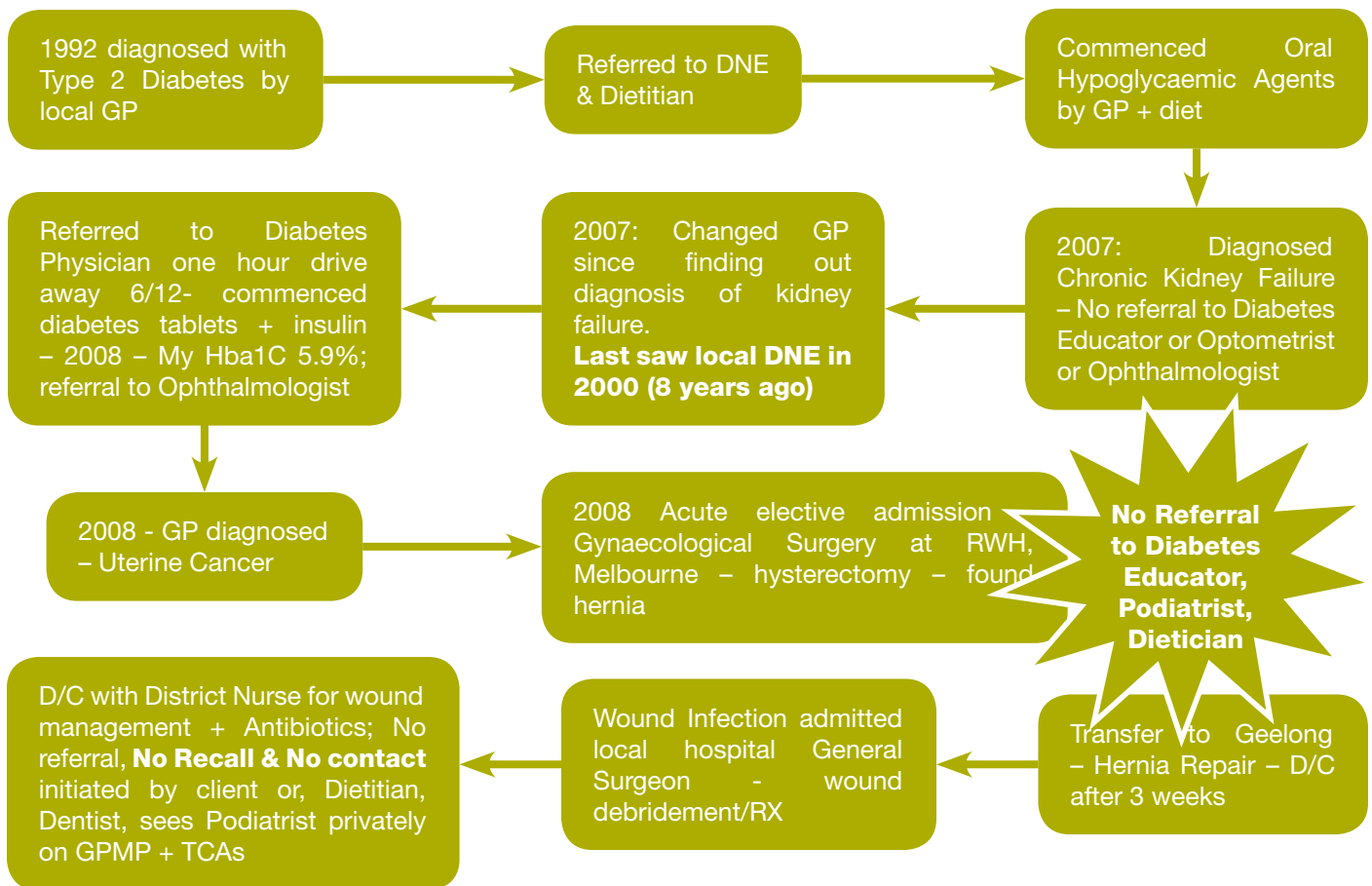
Consumer B" Travel for Specialist Care".



Consumer C: “Dropping Out of the System/Opportunistic Referral/Re-entry”.



Participant D: “Dropping out of the system/Oppportunistic Referral/Re-entry”.



Participant E: “Discharge Planning & Travel for Rural People from Melbourne”.

