



**Chronic Conditions Self Management 2008-2010 Project**

**Partnership activities with  
Rockingham Kwinana Division of General Practice**

**Report from first round community discussion sessions**

**March 2009**



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#### ***Introduction***

The Consumers Health Forum of Australia (CHF) is undertaking a two-year project in chronic conditions self management to engage health consumer networks in policy development and implementation in local and national self management programs and strategies. The CHF *Chronic Conditions Self Management 2008-2010 Project*<sup>1</sup> (the project) is funded by the Australian Government Department of Health and Ageing under the *Australian Better Health Initiative*.

CHF has partnered with three Divisions of General Practice to undertake project activities at the local level. These Divisions are:

- Adelaide Northern Division of General Practice (SA)
- Murrumbidgee General Practice Network (NSW)
- Rockingham Kwinana Division of General Practice (WA)

At the local level, project activities include two rounds of community discussion sessions. The first round of discussion sessions aim to bring together local consumers to share ideas about what consumers need to effectively self manage chronic conditions. This consultation will inform consideration of local strategies to support self management approaches, as well as the development of a consumer resource by CHF to assist consumers to self manage their chronic conditions.

The second round of discussion sessions (to be held in the second half of 2009) will engage a mix of local consumers, community organisation representatives, health professionals and other interested parties to provide feedback to CHF and partner Divisions to inform the ongoing development of local self management support strategies, as well as the CHF consumer resource.

#### **Report focus**

In March 2009, CHF undertook the first round community discussion sessions with Rockingham Kwinana Division of General Practice (the Division). Two discussion sessions with local consumers were held – in Kwinana on 23 March and in Rockingham 24 March.

On 25 March 2009, CHF participated in a meeting of the ‘Healthy Lifestyles Reference Group’, a group of local health providers who work with consumers with chronic conditions.

This paper reports on these Rockingham Kwinana activities and their key outcomes to inform the ongoing work of this project.

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<sup>1</sup> For more information on the CHF *Chronic Conditions Self Management 2008-2010 Project* please see the project page on the CHF website at <http://www.chf.org.au/projects/PROJ14/index.asp>

## ***Community discussion sessions***

### **Planning**

The two community discussion sessions were organised and planned in partnership with the Rockingham Kwinana Division. The decision to hold two sessions instead of the one was based on advice from the Division that the two towns that make up the Division area – Rockingham and Kwinana – are quite distinct communities.

Flyers advertising the sessions were developed by CHF with input from the Division. These flyers were distributed by the Division to people who have participated in the six week Lorig Chronic Disease Self Management course offered by the Division. CHF also distributed the flyers to member organisations located in Western Australia, as well as national members who had expressed interest in the project through other CHF communications or project activities.

The Kwinana session was supported by the Kwinana Seniors Club, which provided the venue free of charge. The Rockingham session was supported by the City of Rockingham, which provided the venue and catering free of charge. CHF appreciates the significant work of these groups, together with the Rockingham Kwinana Division, in making these activities possible.

A draft copy of this report was provided to the Division for comment and verification of the report as a true representation of the discussions.

### **Participants**

The Kwinana discussion session was attended by 17 health consumers, who are members of the Kwinana Senior Citizens Club and most of whom have undertaken a six week Lorig Chronic Disease Self Management course and or had undertaken the Metropolitan Healthy Lifestyle Program for newly diagnosed Diabetic through the Division. A representative of the WA General Practice Network and a representative from Active Ageing WA were also in attendance.

The Rockingham discussion session was attended by 14 health consumers, all of whom have undertaken the six week Lorig workshop and or the Metropolitan Healthy Lifestyle Program through the Division, together with a representative of the WA General Practice Network and a Council member from the City of Rockingham.

Three to four staff from the Division, as well as a member of the CHF Project Reference Group, also attended both sessions and acted as table leaders during small group discussions. Both sessions were facilitated by the CHF project manager. A Division representative assisted with note taking for both sessions.

CHF thanks all participants for their input to the discussions.

### **Program**

The objectives and program for the discussion sessions were developed by CHF in consultation with the Division. The aim of the sessions was to hear from consumers about what they need to self manage their chronic conditions. The specific objectives were:

- To update consumers on self management approaches, including the work of the Rockingham Kwinana Division of General Practice.
- To discuss consumer experiences about managing their chronic conditions – what works and what doesn't?
- To seek ideas from consumers to improve local and national supports for self management approaches, including consumer resources (such as booklets) and local initiatives.

The sessions began with a welcome and introductions. Participants were then asked to complete a short survey on what self management means to them. Information collected through this survey will provide benchmark data to assist CHF in the evaluation of this project.

Two presentations were then provided. CHF provided information on the work that it does and on the aims, objectives and key activities of its *Chronic Conditions Self Management 2008-10 Project*. This included an overview of work completed to date for this project, such as the outcomes of a National Planning Workshop with CHF consumer representatives and key stakeholders held in August 2008<sup>2</sup>. CHF described what self management meant for workshop participants and the kinds of supports, skills and resources reported as being necessary to enable consumers to effectively self manage.

The Division then provided information on the kinds of supports and services it provides to assist local consumers in self managing chronic conditions. After a short break, a member of the CHF project Reference Group provided an example of a consumer driven self management program established in Melbourne.

Participants were then asked to brainstorm at their tables what skills, resources and supports (formal and informal) people need to effectively self manage their chronic conditions.

In considering resources, participants were informed that CHF will be developing a consumer resource to assist people to manage their conditions as part of this project. Participants were asked to consider a handout that briefly outlined some ideas for this resource that have been proposed by CHF member organisations and consumer representatives to date.

In considering supports, participants were asked to reflect on possible local initiatives or programs that they feel may assist them, which could involve the Division, local Council or community groups.

## **Outcomes**

As there was substantial alignment between the discussions and feedback from the two sessions, the key consumer views and perspectives from both sessions are presented together below. Where an issue was specific to one session, this is identified in brackets.

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<sup>2</sup> The National Planning Workshop report is available on the CHF website at <http://www.chf.org.au/Docs/Downloads/499-ccsm-workshop-report-aug08.pdf>

Participants discussed a number of skills, resources and supports that consumers need generally to effectively self manage their chronic conditions. This broad discussion is presented below under headings identifying key themes. Specific participant reflections on and suggestions for possible local initiatives or programs that could assist local consumers in self managing are identified in boxed text within this discussion.

### ***What consumers need to effectively self manage – local perspectives***

#### **Access to affordable, appropriate and well-coordinated health care services**

Consumers need access to general practitioners (GPs) who are understanding, have the time to talk with them about their condition in lay terms and who can provide ongoing support. They also need access to a range of other health providers who are “on the same page” and who can communicate effectively with them and with each other. Consumers need validation from their health providers, need to feel free to ask questions and need to be supported to be actively involved in decisions effecting their health and well being.

Consumers also need a choice of health providers to ensure they can choose someone with whom they can work effectively in managing their health.



Kwinana discussion session participants

*Permission obtained from participants for photo to be taken and reproduced in CHF publications*

Consumers need assistance in accessing the range of health providers they need and in coordinating their various appointments. Preferably, this coordination would be provided through general practice [Kwinana]. A consumer driven one-stop-shop of health providers would improve access to the range of health providers that consumers with chronic conditions may need to see [Kwinana].

The development of a shared health record, owned by consumers, would benefit consumers by facilitating health care communication and coordination [Rockingham].

The barriers of long waiting lists to access health providers and the inhibitive costs of services need to be addressed. These barriers are a particular problem in relation to consumers

obtaining repeat prescriptions through their GPs [Rockingham]. Consumers must be informed about costs of health care services and treatments in advance [Rockingham].

In relation to mental health, it is particularly crucial that the health system provides early intervention services and supports to ensure consumers with mental health issues receive prompt and appropriate care [Rockingham].

Finally, consumers need staff of social support services outside of the health system, e.g. Centrelink, to be trained in working effectively with people living with chronic conditions to ensure appropriate and respectful service delivery [Rockingham].

Locally, participants called for more GPs. They also suggested the establishment of a local script service to provide timely and affordable access to repeat medicine prescriptions, thus reducing the need to see a GP, which can involve waiting periods and unreasonable costs.

Participants also identified the need for a local specialist centre to reduce local consumers having to travel to Perth for specialist care [Rockingham].

### **Access to interactive support groups and other self management supports**

Consumers need access to interactive courses and support groups for people living with similar conditions to them. Such courses and support groups are extremely beneficial for consumers living with chronic conditions, not only for learning from peers but also in facilitating social networks and nurturing self-esteem.

*“You learn from interaction with the group, not just from the facilitators of the course!”*–  
Kwinana participant comment

Self management courses need to recognise that many consumers live with multiple health conditions and that consumers have individual needs. They should recognise that some consumers living with chronic conditions are carers for others [Rockingham].



Rockingham discussion session participants

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Courses should be framed in positive language in terms of improving health and well-being rather than focusing on the negative term of 'chronic conditions' [Rockingham]. At the conclusion of self management courses, participants need ongoing supports and reminders to self manage. Consumers would benefit from one-on-one mentoring from peers who are trained in providing support, and also from telephone help lines for specific health conditions.

Consumers also need access to social environments and interest groups that are not related to health conditions. The 'Kwinana Senior Citizens' [Kwinana] and the 'Men's Shed' [Rockingham] are good examples of avenues for such social support.

The vast majority of participants have undertaken a six week Lorig course in chronic disease self management run by the Division. Participants reflected very positively on their experiences and learnings from this course, and many have since maintained contact with fellow course participants.

Locally, participants recommended that more interactive and ongoing support programs and networks be established for people living with chronic conditions, with the support of the Division or community networks. They also suggested a system be established through which consumers can opt to receive a regular telephone call from a health mentor or coach to remind them to self care.

Participants suggested that a training package or resource for self management peer leaders or mentors be developed [Kwinana].

### **Access to consumer-friendly, up-to-date information**

Consumers need access to information on health conditions, local services/supports and to support self management approaches. This information needs to be consumer-friendly and respectful, easy to understand and up-to-date. Consumers would benefit from a resource that empowers them to ask questions about their health care with confidence.

Consumers want information to be provided to them by health providers and others in a coordinated way so as to reduce duplication, information over-load or conflicting messages.

As with self management courses, resources for consumers need to recognise that many consumers live with multiple conditions and have individual needs; and further, resources should be framed in positive language in terms of improving health and well being.

Locally, participants identified the need for a local directory of health and community services and programs.

Participants also identified the importance of having access to the community newspaper to find out what activities and programs are happening locally. [Rockingham]

### **Access to appropriate transport options**

Inadequate transport options can be a major barrier for consumers in accessing health care, support services and social supports. Consumers need affordable and practical transport options, as well as adequate disabled parking and drop off zones, to enable them access to the range of services and supports that they need.

Locally, participants identified the need for a free or affordable bus service (e.g. a shuttle bus), as well as increased disabled parking and drop off zones, particularly at local hospitals.

Participants suggested the establishment of a car pooling system (e.g. through the Division, their GP or the local hospital) with which consumers could register to offer lifts to others or to seek transport assistance from others to attend medical appointments [Rockingham].

### **Access to safe and mobile-friendly communities**

To be active members of the community, consumers need accessible public and community spaces. They need to feel safe and secure in their community and to have appropriate infrastructures to assist their mobility, e.g. level footpaths, ample and appropriate public seating and hand railings.

Locally, participants identified the need for Council to ensure that footpaths are level so that they are safe and accessible to consumers with mobility issues.

Participants also identified the need for all Council, public and community buildings to have disabled access, hand rails and appropriate seating.

Participants identified two features of the Rockingham shopping plaza that inhibit mobility and that they would like addressed:

- 1) there is a lack of appropriate public seating – more seating is needed with arm rests to support people to get out of them;
- 2) one of the two post offices has recently been closed – this should be re-opened to provide better access. [Rockingham]

### **Access to affordable and ongoing home supports and aides**

Consumers need access to affordable home supports (provided through local Councils), including support with meals, home and garden maintenance, and carer respite.

Friends and family play a crucial role in providing support for consumers managing their health; however, some consumers with chronic conditions are socially isolated. Systems need to be in place to care for and monitor these vulnerable consumers.

*“With age, your circle shrinks and you slow down. This needs to be acknowledged” –  
Kwinana participant comment*

Consumers also need timely and affordable access to aides and equipment, such as wheelchairs and walkers.

Participants suggested a system be established locally for consumers living alone to register with if they would like a regular telephone call or visitor to check on their well being [Rockingham].

Participants proposed that telephone companies should provide a discount for consumers living with chronic conditions to assist such consumers in keeping in touch with family and friends – recognising the important role that these people play in supporting consumer to self manage [Rockingham].

They also identified the need for improved access to aides and equipment – reflecting that although these supports are provided through pharmacy, there is often a significant waiting period [Rockingham].

### **Access to affordable and practical exercise options**

In order to stay physically active, consumers need access to affordable, practical and non-judgmental exercise options, such as gyms and pools. They also need support to incorporate physical activity into their daily lives.



Kwinana Discussion Session participants during CHF feedback session

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Social networks are particularly useful for motivating consumers living with chronic conditions to remain active. The ‘Prime Movers’ is a good example of a social exercise program [Rockingham].

Locally, participants identified the need for more affordable and practical exercise options. In particular, participants want more public swimming pools, which offer wider lap lanes as well as specified times for slower swimmers and hydrotherapy sessions.

Participants also suggested that an exercise buddy system be established, perhaps through the Division, to encourage consumers to stay active through peer links.

Further, participants suggested that a resource be developed to motivate consumers to incorporate movement into their daily lives. [Rockingham]

## Evaluation

Twelve Kwinana and 15 Rockingham participants provided evaluation feedback on whether the discussion sessions met the stated objectives and participants' need.

All respondents thought the objectives of the discussion sessions had been met. All but one [Kwinana] respondent said that they were satisfied or very satisfied (the majority) with the content. The one unsatisfied respondent did not provide further comment and provided positive responses for all other questions.

All respondents thought that the people who provided the information at the discussion session were skilled and professional in their approach.

When asked about the participants next steps in relation to what they had heard and learnt from the session, most respondents answered that they would like to be involved in future information sessions and support groups, as well as in the future project activities. Finally, all comments received on the venue and catering were positive.

Free text comments provided by respondents included:

*A lot of interesting ideas were raised* – Kwinana participant

*All facilitators were clear and had time to answer questions, which was good* – Kwinana participant

*See you in June!* – Rockingham participant

*They seemed to listen to what we want and need* – Rockingham participant

*One word – brilliant* – Rockingham participant

## ***Healthy Lifestyles Reference Group Meeting***

On the invitation of the Rockingham Kwinana Division, CHF participated in a meeting of the 'Healthy Lifestyles Reference Group' – a group made up of local health providers working with consumers living with chronic conditions – on 25 March 2009. This Group is coordinated through the Division.

The Health Consumers Council of WA (HCCWA) was also invited to and attended this meeting.

### **Program**

The Healthy Lifestyles Reference Group meets on a quarterly basis to share information on the work of its members in the local community.

Prior to having their normal meeting, this Group invited CHF to present an overview on the consumer feedback received at the community discussion sessions held on the previous two days. Group members then discussed these issues and considered how this consumer feedback could inform their work. In so doing, the Group identified a number of barriers and opportunities in terms of local supports for consumers with chronic conditions.

CHF thanks the Division and the Healthy Lifestyles Reference Group (the Group) for providing this opportunity. The Group was extremely responsive to the consumer feedback given and demonstrated great enthusiasm and commitment to improving health outcomes for local consumers living with chronic conditions.

CHF looks forward to the participation of members of this Group in the second round community discussion sessions to be undertaken by CHF and the Division in June 2009.

### **Outcomes**

#### ***Local barriers to supporting consumers with chronic conditions***

The Group discussed the restrictive eligibility requirements for many health programs, which limits consumer access. They also discussed the limited number of self management programs and allied health professionals available in the Rockingham Kwinana area. In relation to self management courses, the Group identified the limited supports available for self management peer support leaders, which can lead to peer leader burn-out. These concerns have resulted in the limited use of peer leaders by the Division and other services in program delivery.

The Group acknowledged the concerns raised by consumers in relation to transport problems, identifying that the distance between the railway station and the hospital in Perth was a real barrier for consumers in accessing services. The Group also identified difficulties they face in getting relevant information on health conditions and services to consumers without over-loading them.

In relation to Indigenous consumers, the Group discussed difficulties faced by these consumers in accessing health services and the need for services to be more culturally sensitive. The Lorig chronic conditions self management course, it was noted, is not

structured in a way that is appropriate for Indigenous people. Further, the Group identified self management as being a low priority for most Indigenous consumers due to the number of more pressing life issues they face.

Finally, the Group discussed barriers to optimal health outcomes for consumers stemming from the inappropriate use of medicines. This discussion was prompted by the presentation of the outcomes of a recent study by the Division into Home Medicines Reviews. The Group noted that consumers can currently only access a Home Medicines Review with referral from their GP and that access and take up may be increased if consumers could self-refer to the program.

### ***Local opportunities for supporting consumers with chronic conditions***

The Group discussed possibilities for improving local training and support for peer leaders involved in self management programs. This support could be improved, for example, through the establishment of a local peer leaders' network, which could provide capacity building opportunities for peer leaders to de-brief, raise issues and learn from each other.

In relation to information provision, the Group discussed opportunities to improve the online directory of services managed by the City of Rockingham. The Group also discussed the benefits of having a complimentary telephone line service for consumers without internet access to gain access to this directory. The possibility of including computer training in local self management courses was also discussed as this could provide consumers with the skills to utilise the internet as an ongoing support.

Further, the Group discussed a range of local programs and resources that they could contribute to and help distribute information on to consumers, which could improve referral pathways. In relation to Indigenous consumers, the Group discussed a booklet of local events (from April-November 2009) currently being developed for Indigenous community members, which Group members are invited to contribute to if they have activities or programs coming up that Indigenous people may be interested in participating in.

The WA General Practice Network also advised the Group of its recent application to the Australian Government Department of Health and Ageing for funding under the *Australian Better Health Initiative* to develop an Indigenous version of the Lorig chronic conditions self management course.

Finally, the Division invited HCCWA to nominate a local consumer representative to join the Group to provide an ongoing consumer voice. (HCCWA has agreed to this and is in discussions with the Division on a suitable representative.)

## ***Summary of outcomes to inform next steps***

### ***CHF project work***

These Rockingham Kwinana discussions have highlighted the needs of consumers living with chronic conditions in relation to access to:

- affordable, appropriate and well-coordinated health care services
- interactive support groups and other self management supports
- consumer-friendly, up-to-date information
- appropriate transport options
- safe and mobile-friendly communities
- affordable and ongoing home supports and aides
- affordable and practical exercise options.

This feedback will inform CHF's policy development on self management approaches and related issues, which will be reported to the Australian Government Department of Health and Ageing and will continue to inform CHF communications with stakeholders. This will help shape the health system in ways that meet the needs and expectation of health consumers.

These local discussions also provided valuable input to inform the CHF development of a consumer resource to assist people in managing their chronic conditions. In particular, these discussions raised the need for consumer information that:

- empowers consumers to ask questions about their health care with confidence
- recognises that many consumers live with multiple conditions and have individual needs
- is framed in positive language in terms of improving health and well being
- supports the work of self management peer leaders and mentors
- motivates to incorporate movement into their daily lives.

These discussions further emphasised the need for information to be consumer-friendly and respectful, easy to understand and up-to-date.

### ***Local possibilities***

A range of local consumer issues were raised through these discussions that may be progressed by the Rockingham Kwinana Division, local Council or other community groups as appropriate. These issues may also inform local policy input into State health and community arrangements.

The discussions raised a number of consumer recommendations for improving local support for people living with chronic conditions, including:

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- establishing a local script service and specialist centre
- providing more interactive and ongoing support programs and networks
- developing a telephone health mentoring/coaching service
- developing a local directory of health and community services and programs
- improving access to the local community newspaper
- providing a free or affordable bus service (e.g. a shuttle bus), increasing disabled parking and drop off zones, and establishing a car pooling system
- improving local footpaths; disabled access, hand rails and seating in community/public buildings; and access to aides and equipment
- reopening the recently closed Rockingham post office
- establishing a service to monitor people living alone with chronic conditions
- providing consumers living with chronic conditions with a discount on phone calls
- providing affordable and practical exercise options, including an exercise buddy system.

## **Conclusion**

These first round community discussion sessions and local stakeholder consultations provided an invaluable opportunity for consumers and health providers to inform the directions of the CHF *Chronic Conditions Self Management 2008-2010 Project*, as well as the work of the Rockingham Kwinana Division of General Practice in supporting local consumers living with chronic conditions.

Participants of the community discussion sessions clearly articulated, from a consumer perspective, what good self management involves and what consumers need in order to self manage. Participants discussed the role of health providers and community networks in supporting them to be in control of their health and well being. They also discussed a range of factors that impact on self management – including information provision, access to appropriate exercise options, social contacts, transport and home supports.

In relation to the development of consumer resources to assist consumers to self manage effectively, participants emphasised the importance of using language that is meaningful to consumers and easy to use, and to recognise co-morbidities and that consumers have individual needs. The information obtained from both local consumers and health providers will guide CHF in developing its consumer resource for this project.

CHF looks forward to returning to Rockingham Kwinana Division in June 2009 to continue work with the local community on this important project.

## **Contact Us**

Further information on this workshop and activities under this CHF project can be found at:

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This report reflects discussion at the CHF 'Chronic Conditions Self Management Project 2008-2010' First Round Discussion Sessions with Rockingham Kwinana Division between 23 and 25 March 2009 and does not necessarily reflect the views of the Consumers Health Forum of Australia, the Rockingham Kwinana Division of General Practice nor the Australian Government Department of Health and Ageing.