

### SELF-MANAGEMENT: A new era dawns.....

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#### *Tasmanian Sharing Health Care Initiative Project*

Chronic conditions are one of the greatest health challenges facing Australia in the 21st Century. It is estimated that currently around 2.5 million Australians have a chronic condition and by 2016 this will rise to 3.5 million. Evidence in Australia and overseas suggests that self-management programs can assist those with chronic conditions to improve their quality of life, by equipping them with knowledge, skills, and confidence to better manage disease-related problems.

The long-term impacts of chronic condition self-management (CCSM) are positive, with data from two-year and four-year follow-up studies of the six-week "Chronic Disease Self-management program" (CDSMP), developed at Stanford University by Professor Kate Lorig, suggesting that the effects on reduced outpatient visits to health services and reduced pain were still apparent<sup>1</sup>. Due to the nature of chronic conditions, significant clinical improvements may not always occur; rather, it is the slowing of the deterioration in clinical conditions that is achievable.

Evidence also indicates that peer leaders as well as health professionals can just as effectively deliver these self-management programs. As the effectiveness of such interventions gathers evidence, other modalities of self-management interventions are also being trialed, including individual, group, telephone, and self-instruction formats. Newer delivery models, such as telephone and Internet programs, may be a promising means of delivering effective self-management to those under-represented in face-to-face self-management programs. Trials of Internet self-management programs are currently underway at Stanford University in the US<sup>2</sup>.

In a review of research relevant to the delivery of self-management support, Michael Von Korff and colleagues<sup>3</sup> found a strong evidence base exists that supports self-management principles. Increasing levels of patient confidence and self-efficacy appears to be important, as is ongoing follow-up and support in sustaining self-management behaviours and improved patient

outcomes. Research suggests that self-management outcomes are particularly strong when interventions involve collaboration with patients and other health professionals in identifying priorities, setting goals, and defining specific plans towards goal achievement.

The research has reached the point where it has become increasingly important to conduct more extended demonstration trials and to explore the issues involved in integrating self-management programs within everyday health care settings as part of standard practice. In this respect, the Commonwealth Government has committed \$14.4m to the development of self-management of chronic illness in Australia through the Sharing Health Care Initiative (SHCI), which was part of the 1999-2000 Federal Budget. A further \$21.8m has now been allocated in the 2003-2004 Federal Budget over the next four years to implement CCSM more broadly into the Australian health care system.

Most of the funding under the SHCI is provided for 12 demonstration projects that have been implemented to test a range of chronic condition self-management models in the Australian context. The SHCI arose from the work of existing overseas and Australian self-management programs already implemented by a number of non-government organisations, notably, in Australia, Arthritis Foundation Australia.

Part of the funding for the SHCI is also directed towards testing a range of education and training programs and clinical guidelines developed by the Flinders University Human Behaviour & Health Research Unit, and the Royal Australian College of General Practice (WA Research Unit). A national evaluation framework is evaluating the organisational processes across the demonstration projects in relation to the health system (people, technology, and infrastructure), and care-related processes from the client, carer/family, health service provider, and community perspectives.

Workforce development and the dissemination of CCSM have become important as interest in CCSM rapidly develops. Professor Lorig has had

had a significant influence on the implementation of CCSM in Australia, as well as the Expert Patients program which is part of the NHS in the UK. Her recent tour of Australia as a guest speaker and facilitator at a variety of conferences and meetings in Victoria, Tasmania, and Queensland have been important in promoting the ideas and research which underpin CCSM.

While she was in Australia, Lorig emphasised the importance of a number of factors that contribute to the success of SHCI demonstration projects. These included:

- The engagement of key stakeholders, such as volunteers, consumers, health organisations and those within the health system, in a very meaningful and collaborative way, has been integral to the success of CCSM programs.
- The inclusion of the CDSMP with its' strong evidence base, as an intervention offered by many of the projects, has provided a tangible and credible resource for communities to take up and embrace.
- The use of a consistent and national evaluation framework across all projects within the SHCI has led to a high level of interest from a wide range of stakeholders in the future results of the projects. This will be further strengthened and informed by the use of local evaluation frameworks to identify and tease out the more project specific aspects of the self-management strategies, and their impact and effectiveness.
- The development of strong, supportive and aligned governance structures so as to facilitate the management of the more complex inter-professional and inter-organisational relationships and collaborations.
- Recruiting CDSMP participants requires flexible referral paths for consumers as well as health providers and GPs. There was also a strong recognition that while "word of mouth" referrals worked well among consumers, as well as among health and community workers, this often took time, and programs needed to maintain a presence and momentum for this to work effectively, and to maintain program credibility.
- Client involvement in many of the projects has also been enhanced through access to a variety of other self-management orientated activities that support behavioral lifestyle changes or access to

information or services. These activities have also offered opportunities for the development of social supports, as well as the sharing of resource information, knowledge, coping skills and experiences among program participants and family members, and peers.

- Collaborations with surrounding health, education and social systems have led to the exploration of the practical issues around using and integrating a CCSM approach, as well as the development or strengthening of partnerships and more effective resource utilisation. This commitment to the work and concepts of CCSM across a number of sectors will be essential for longer-term sustainability of CCSM.

The achievements in chronic condition self-management research in Australia was acknowledged by Dr Lorig as being world-class and provided a model for other countries to follow. Dr Lorig did, however, identify several issues key to ensuring sustainable CCSM programs in the Australian context. These issues include ensuring that:

- there was strong, co-ordinated and effective quality control infrastructures in place for CDSM program delivery. This would cover the training of leaders; co-ordination and delivery of courses; meeting all licensing requirements, as well as taking a role in the co-ordination of the development of the program to meet other cultural or environmental contexts;
- CCSM programs needed to be accessible and applicable to a wide range of participants, in a variety of settings, and across all age groups; and
- peer leaders, volunteers and paid program staff are acknowledged as the key to effective self-management program delivery, and that ongoing support and appreciation for their roles is clearly demonstrated through organisational structures.

### ***Where to from here?***

With another 12 months before the SHCI demonstration projects are completed, there is still much to be learnt about chronic condition self-management within the Australian context. The findings of the National Evaluation, due in late 2004, will go a long way to adding to the evidence base for these delivery models.

With funding provided over the next four years, the Commonwealth is undertaking a policy

development and implementation process that will be informed by broad consultation. While these consultations are currently in the preliminary stages, there appear to be several key factors that influence the integration of chronic condition self-management into the Australian health care system. These factors include:

- recognising existing networks and partnerships with GPs, other health providers, non-government organisations, committed consumer “champions”, and private health insurers;
- the importance of consumers and community organisations in program promotion, co-ordination and delivery and the need to have flexibility in ways of delivery or ability to adapt material for particular groups;
- clear identification of roles and responsibilities at all levels of the health system, including Commonwealth, state/territory, local government levels, non-government and other organisations;
- a coordinated response to incorporating CCSM into the education and training sector;
- the challenge of multidisciplinary care for GPs, allied health professionals, nurses, and Aboriginal health workers;
- working with existing health funding structures and looking at ways of integrating CCSM principles into them, as well as identifying other

funding opportunities and partnerships to complement this work to ensure CCSM sustainability;

- working towards increasing participation levels in self-management programs by people newly diagnosed. Through earlier access to such programs, and with support through the health system along a self-management model, better clinical results in terms of slowing disease progression over time may be possible, as well as clients having a greater sense of empowerment and participating as an active partner in their healthcare; and
- developing and promoting flexible and innovative self-management approaches to overcome issues of cultural, geographical and social isolation to ensure access to self-management for all who desire it.

There is now considerable interest in CCSM in Australia, but much of the work is still in the early stage of development. It is important that the Commonwealth continue to support events such as the National Chronic Condition Self-Management Conference to be held in November this year<sup>4</sup>. Sharing our observations, learning and experiences is a critical part of the task of rolling out CCSM for the future. This special issue of the Australian Journal of Primary Health is an important step in this direction.

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- 1 Lorig, K.R., Sobel, D.S., Stewart, A.L., Brown, Jr. B.W., Ritter, P.L., González, V.M., Laurent, D.D., & Holman, H.R. (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing utilization and costs: A randomized trial. *Medical Care*, 37(1), 5-14; Lorig, K.R., Ritter, P., Stewart, A.L., Sobel, D.S., Brown, B.W., Bandura, A., González, V.M., Laurent, D.D., & Holman, H.R. (2001). Chronic Disease Self-Management Program: 2-Year Health Status and Health Care Utilization Outcomes. *Medical Care*, 39(11), 1217-1223.
  - 2 Stanford Patient Education Research Centre: <http://patienteducation.stanford.edu/index.html>
  - 3 Von Korff, M., Schaefer, J., Ludman, E., Parkerton, M., Davis, C., & Wagner, E. (2003). The Evidence-Base for Collaborative Self-Management Support. PowerPoint presentation.
  - 4 The Department of Health and Ageing will hold a National Chronic Condition Self-Management Conference in Melbourne from 12-14 November 2003. Speakers will include national and international participants from Australia, UK, US, and NZ including Senator the Hon Kay Patterson, Commonwealth Minister for Health, Mr Philip Davies, Deputy Secretary, Commonwealth Department of Health and Ageing, Dr Kate Lorig of Stanford University, Dr Sunjai Gupta, Head Expert Patient Programme, Department of Health, UK. This conference will build on current CCSM activities across Australia and will provide a forum for stakeholder consultation and input into the next phase of CCSM in Australia.