

## **Project information**

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Title of project: An investigation of successful components in the implementation, support and evaluation of the person centred approach across care settings: consumer participation and translating research into practice.

Study area: Quality improvement and systems measurement

Fellow's organisation: Northern Health

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## **Project summary**

### ***Top three outcomes***

1. Identified key strategic actions beneficial in the Victorian context for improving community and consumer participation to enhance person centred care for older people in health services.
2. Documented successful change management approach to improving person centred care across care settings.
3. Discovered specialised food that provides a significant improvement in the eating experience and outcomes for people with dysphagia.

### ***Main activities undertaken***

- ☐ Reviewed the implementation and ongoing management of programs relating to self-management of chronic disease in regional and urban locations in the UK.
- ☐ Examined a range of consumer involvement programs specific to enhancing person centred care across care settings.
- ☐ Studied a major urban hospital's approach to the care of older people and how consumer involvement is linked to service planning and delivery.
- ☐ Explored the successful expansion of exercise classes for over 60's across locations in the UK.
- ☐ Assessed the outcomes of eleven years of food technology research in practice at a large residential hospital for older persons and reviewed the development and application of dementia friendly physical and social environments in the hospital environment.
- ☐ Investigated the translation of research to develop dementia-friendly physical and social environments for day respite and complex care service delivery models.
- ☐ Appraised the application of specific person centred models of residential care.
- ☐ Reviewed a model of community participation involving statewide operational policy, service planning and development for older people.
- ☐ Scrutinised a statewide program of peer mental health counselling for older people.





## ***Major learning's***

- 📖 Successful consumer and community participation in health service settings requires significant organisational commitment and action to realise the benefits and break down system and ideological barriers.
- 📖 The implementation of person centred care in any health care setting requires a quality improvement framework that focuses on more practical educational approaches that directly address clearly identified issues and challenges.
- 📖 The sustainability of person centre care in any health care setting requires management commitment and strong leadership that fosters the empowerment of direct care staff to address the needs of the older person as identified and which provides ongoing support and engagement within the quality improvement framework.
- 📖 The successful recruitment and retention of consumers in active participatory roles within health care settings is related to three key elements: a clearly defined role, role value and visible, positive outcomes.
- 📖 The physical environment is very important in creating the right environment for providing information and encouraging clients to provide their views about the care they receive in a health care setting.
- 📖 To maximise the benefits of research evidence, the translation of research to practice to improve the care of older people requires innovative thinking, risk-taking and a commitment of resources at all levels of the organisation.
- 📖 Overseas models of dementia friendly physical and social environments that are financially comparable to traditional residential care facilities have been inextricably linked to existing infrastructure that provides either clinical or administrative support.
- 📖 Person centred care can be seriously undermined in all health care settings by a lack of understanding about the role of food.

## ***Lessons for the Victorian healthcare system***

- 📖 Consumer participation in Victorian healthcare organisations is at a crucial stage where immediate benefits of a few key short term actions can set the foundation for moving forward in partnership.
- 📖 To increase consumer and community participation at the policy and planning level, State government could involve older consumers through an advisory committee structure that links to health service community advisory committees.
- 📖 Lay led programs in health care management can contribute to the State healthcare system significantly and should be considered a fundamental component within all health service organisations that

provides sustainable benefits to consumers and to the healthcare system.

-  Dieticians should hold management positions in kitchens responsible for feeding people in health care settings to ensure that food plays the appropriate role in the quality of care provided.
-  People experiencing dysphagia in Victoria could benefit significantly from reconstituted food that increases appetite and has better nutrition than traditional pureed and minced diets available currently. Health care organisations are likely to find it cost effective given that the high cost of supplements is significantly reduced with this food as part of the treatment for dysphagia.
-  Person centred care in a dementia friendly environment can be facilitated in residential care settings without significant cost differentiations to more traditional care environments – state facilities could be pilot sites for the implementation of Department of Human Services resources currently under development that provide information on creating such environments.
-  Person centred care in any health care setting can be successfully implemented and sustained with a practical educational approach that provides training and ongoing support.

## **Description of the study itinerary**

### ***South West England***

#### ***South West Peninsula Strategic Health Authority (SWPSHA)***

The SWPSHA covers Devon, Cornwall and the Isles of Scilly and is the local headquarters of the National Health Service (NHS). There are eleven Primary Care Trusts (PCTs) in the South West Peninsula, eight in Devon and three in Cornwall. There are five acute NHS Trusts (large hospitals) in the area and these are located in Truro, Plymouth, Torbay, Exeter and Barnstaple.

#### ***Expert Patient Program (EPP)***

The Expert Patients Program (EPP) has been introduced across the National Health Service to facilitate lay led self-management training programs for clients with chronic diseases. It is a scheme to help people with long-term health conditions take control and have more power over their health. The aim is to attain the greatest possible quality of life by enabling individuals to live with their conditions and teaching them skills to manage both the symptoms and the challenges of chronic disease. The course aims to empower individuals to regain control over their lives and their disease.

The NHS initially appointed two principal trainers to oversee training and delivery of the EPP at a national level, and teams of trainers and senior trainers with responsibility for local areas. The intention was to provide all Primary Care Trusts with access to trainers and a senior trainer to advise and oversight all elements of the delivery of PCT courses. Voluntary organisations are encouraged to make contact with NHS trainers to facilitate opportunities for partnerships.

### **The activities undertaken during the visit**

- ‡ Interviewed the senior trainer for the EPP South West of England in Plymouth.
- ‡ Focus group with seven volunteer lay trainers in Exeter St David's.
- ‡ Meeting with four clients who had participated in the program.
- ‡ Interview with lead trainer for the EPP (SW area).
- ‡ Participation in SWPSHA quarterly meeting. I made a presentation to staff from across Cornwall and Devon (approx 40 in attendance) about health services in Victoria and the Victorian Travelling Fellowship Program - reciprocal question/answer time followed. Group included patient and public involvement leads, a number of consultants (psychiatry/geriatrics), commissioning, continuing care and older persons' leads.
- ‡ Interviews with geriatrician, matron, associate director (partnerships and improving health), patient and public involvement officer.
- ‡ Toured facility at Saltash.

## Key lessons learned

- 📖 The implementation and sustainability of a person centred approach to care needs to be firmly placed within a quality improvement framework that incorporates practical educational opportunities.

*The wide range of health professionals interviewed and involved in the focus groups in South West England presented a comprehensive picture of regional issues. However, most salient was that the issues specific to the implementation and sustainability of a person centred approach to care highlighted by these health professionals were very similar to those currently being experienced in both urban and rural health care settings in Victoria. In particular, they voiced concerns about the level of understanding of what constitutes a person centred approach, particularly in the care of older people. Although the NHS provides clear policy direction, on the ground, this regional health authority was struggling with change management issues. Efforts put into professional development and education lacked ongoing support so management and clinicians appeared hard pressed to identify successful examples of person centred care for older people that were sustained. Given the resources and significant work already completed around improving the care of older people and in particular to patient involvement, these findings were disconcerting. What was ultimately revealed was that the model of improvement advocated by the NHS was not really being appropriately or fully utilised across the health authority. Education being provided to staff at various levels was not supported in practice as the various organisations (for example hospital and primary care trusts) systems and processes were often barriers to change. Pockets of success were evident, such as a particularly good example of a Patient Advice and Liaison Service in Plymouth, but this was largely the result of a particular middle manager rather than a replicable model.*

- 📖 Programs targeting self-management of chronic disease are likely to be more successful in recruiting and retaining lay trainers if key paid professionals (for example senior trainers, coordinators) also live with chronic illness.

*In the initial stages of the pilot for the Expert Patient Program in the UK, approximately sixty expert patient trainers were appointed by the NHS to develop pilot work with Primary Care Trusts, train volunteer course tutors, and deliver course and support the long term development of EPPs. In all the UK programs reviewed in this fellowship, coordinators and senior trainers who either worked for the program directly or for the Trusts were also living with chronic illness. Lay trainers interviewed clearly indicated the life changing experience of going through the course and why they became trainers themselves.*

*'Seeing someone else who was doing alright – well I thought – I can do this.'*

*'I got so much out of it I wanted to pass it on.'*

*Evaluations in the UK all show the same pattern of results:*

- *physical deterioration is slowed*
- *self-efficacy (active management of health and life) improves*
- *psychological state improves*
- *use of health promoting techniques increases (for example, exercise and relaxation) and is maintained long-term post course*
- *numbers of visits to doctors reduces*
- *communication with doctors improves*
- *fewer hospitalisations and of shorter lengths of stay.*

## **Suitability to own practice and Victorian healthcare system**

### ***Expert Patient Program***

The Chronic Disease Self Management Program in Victoria is based on the same United States program as the Expert Patient Program. However it appears that implementation of the program has not been as focused on being lay led. At Northern Health (NH), the initial pilot evaluation demonstrated some beneficial outcomes but suffered with poor recruitment of volunteers. There is some clear learning's regarding sustainability from the UK that could be of value in revisiting the NH program.

In particular, consideration should be given of the results of the evaluation of the pilot project at NH that identified the peer/clinician leader mix did appear to be preferred by clients (as compared to clinician/clinician led) because they were able to relate to the peer leader who is experiencing chronic illness themselves. Given that the essence of client self-management is not simply about educating patients about their condition or giving them relevant information but rather is about developing patients' confidence and motivation to use their own skills, information and professional services to take effective control over life with a chronic condition, a lay led program is a strong model.

In the UK the pilot phase is over and the structure of funding is now being moved to a community interest company. Community interest companies (CICs) are social enterprise organisations that are overseen by the CIC regulator. The EPP CIC is a not-for-profit organisation that will operate as a business with the principle goal of improving the lives of people with long-term conditions but without tax benefits like charities. Social enterprises are businesses that are driven by social objectives rather than profits or shareholder value. They can be set up by staff and owned on a co-operative basis. The surplus/profits are reinvested into the services they provide or the communities they service. The adoption of this model has promoted some initial tensions in the South West where the relationship between the regional senior trainer appointed to the pilot and local primary care trusts is strained. They now find themselves in direct competition with one local trust that is also offering the tutor courses. However, this model may be of interest to the Victorian healthcare system in terms of financial sustainability.

## **London, United Kingdom**

### **Connect**

Connect works with people with aphasia, a condition that can affect people's ability to talk, read, write, use numbers and understand others. The organisation uses an integrated program of therapy, education and research, encouraging clients to take a positive, proactive approach to learning to live with aphasia and providing opportunities for clients to meet others who have been through similar experiences. Connect develops innovative therapies, influenced and often delivered by people with aphasia. The primary objective of Connect is to help people to accept and adapt to their situation, to re-engage with life after stroke, and to express their ideas and identity. In 2001, Connect was provided funding to increase the participation of service users involvement in all aspects of its work.



Staff at the Connect Drop-in Centre

### **The activities undertaken during the visit**

- ‡ Day visit to the Connect headquarters, drop-in centre and training facility.
- ‡ Interview with Carole Pound, Director and with trainer, Carol Cross.
- ‡ Interview with Gaynor Smith.
- ‡ Observation and visit with clients.

## Key lessons learned

📖 Involving consumers can be challenging because it requires the organisation to question the way it works. It is important to involve consumers at every level of the organisation.

📖 To make sure that consumers are involved in a way that is effective throughout the organisation in the long term, time, resources and a creative approach to new ideas are essential.

*Connect has utilised the model of 'Patients as Teachers' to develop a 'good practice guide' to raise the awareness about stroke from the perspective of people who have had a stroke and of their carers. A good practice guide and companion video has been developed out of the personal stories and care journeys of people and their carers from many different ethnic backgrounds. As a result of sharing their experiences, people made a number of suggestions about their care and how it can be made person centred.*

📖 Involved appropriately, consumers will develop a strong understanding of the organisation and over time are able to offer a great deal of useful information and develop new ideas.

📖 It is important to create the right conditions for involving consumers in health and social care.

*The physical and social environment has been carefully designed to maximise the abilities of Connect clients through the use of colour, appropriate signage and opportunities for interactions with others where they are on more equal footing. So for example, more time is allocated for board meetings and meetings are structured differently so members with aphasia are not under pressure that limits their contributions.*

📖 Involving consumers, particularly those with communication difficulties, requires developing new ways to exchange ideas, making complex information accessible without over-simplifying it.

*Connect has also been involved with the Expert Patient Program, offering practical training and support to tutors and facilitators to develop specific skills and techniques that enable people with communication disabilities to participate in the program.*

## Suitability to own practice and Victorian healthcare system

It is estimated that some 80,000 Australians have aphasia as a result of stroke (Australian Aphasia Association website, 2006). The Connect project specific to increasing service user participation provides some significant lessons that can be immediately useful for the development of consumer participation. In addition, as this work is grounded in improving communication it would be of particular value in the healthcare setting more broadly. As one of my primary roles is research and quality support for the organisation, there is scope to adapt and incorporate educational material with consumer, staff, peak and community organisations with a focus on stroke recovery to develop in-service education sessions for staff to better communicate and involve people with aphasia and others with communication difficulties in healthcare partnerships.

Learning's from Connect can provide information that can raise awareness and provide insights into how to create the right conditions for involving any service-user group in health and social care. At a fundamental level the potential is:

- ◆ to increase knowledge of the issues and challenges that face people who have communication difficulties
- ◆ highlight useful techniques and tips to communicate effectively and compassionately with people experiencing communication difficulties and have productive enjoyable conversations
- ◆ to increase awareness and skills to change people's working environments and practices to make them more accessible and friendly to people with communication difficulties.

### **Greenwich Teaching Primary Care Trust (TPCT)**

Greenwich TPCT serves over 220,000 people living in the south east of London, across a number of health centres and community sites delivering a range of primary and community services. The Trust identifies the Expert Patient Program as part of their approach to partnerships in health.

#### ***Expert Patient Program (EPP)***

As previously indicated, the EPP is a lay led self-management of chronic disease program. In response to the initial NHS mandate, Greenwich ran seven courses, with eighty participants, and recruited and trained six tutors during the pilot phase. Ten additional courses have been completed from which a further twelve tutors were recruited. Greenwich TPCT is also one of ten Primary Care Trusts nationally involved in piloting a course for parents of a child with a long-term health condition or disability. After initial funding from the Department of Health, the program was funded by Neighbourhood Renewal, but now receives mainstream funding by Greenwich TPCT. In addition the Trust is involved in the pilot of two other expert patient programs: the Parent's Courses, run for and by parents of children with long term health conditions and/or disabilities, and 'Looking after Me', a course for adults who care for someone living with a long term health condition or disability.

#### ***Patient Advice and Liaison Service***

The Patient Advice and Liaison Services (PALS) are an essential part of the Patient and Public Involvement System. Implemented in all NHS trusts with the aim of providing information and on the spot help for patients, their families and carers, they are intended to be a powerful lever for change and improvement. PALS are intended to provide:

- ◆ confidential advice and support to patients, families and their carers
- ◆ information on the NHS and health related matters
- ◆ confidential assistance in resolving problems and concerns quickly
- ◆ information on and explanations of complaints procedures and how to get in touch with someone who can help
- ◆ information on how you can get more involved in your own healthcare and the National Health Service locally.

- ♦ a point for feedback from patients to inform service developments
- ♦ an early warning system for NHS Trusts, Primary Care Trusts and Patient and Public Involvement Forums by monitoring trends and gaps in services and reporting these to the trust management for action.

PALS act on behalf of their service users when handling patient and family concerns. They liaise with staff, managers and, where appropriate, other relevant organisations, to negotiate speedy solutions and to help bring about changes to the way that services are delivered. PALS will also refer patients and families to local or national-based support agencies, as appropriate (DoH website).

### **The activities undertaken during the visit**

- ‡ Site visit to Greenwich Teaching PCT
- ‡ Interview with Debby Monkhouse, EPP Trainer

### **Key lessons learned**

- 📖 Programs targeting self-management of chronic disease should be linked to the community for maximising recruitment and retention of consumer participants.

*Greenwich TPCT has over 100 volunteers in the Expert Patient Program. The coordinator identified collaboration with other groups in the community as an important part of recruitment. Key health services, such as community groups and peak organisations, were all targeted. This is also important in financial terms as small amounts of funding can go a long way when there is cooperation with other organisations. The time of courses, venue, support of program participants and lay trainers are also very important to the success of this type of program.*

- 📖 Taking people out of the patient role allows them to better collaborate with health professionals.

*Evaluations of the program in Greenwich have indicated that people who have completed the program feel more confident generally about every day life and more specifically, confident to engage with their doctor(s) and other health professionals. The internal monitoring results to date line up with findings of previous trials and show:*

- 10 per cent more take medicine as prescribed
- 30 per cent show significant reduction in feelings of depression
- 30 per cent report feeling increased levels of energy
- 20–30 per cent felt decreased intensity of pain and/or breathlessness
- 30-50 per cent felt they would not let pain, breathlessness, tiredness or depression interfere with their lives
- 9 per cent fewer visits to GPs
- 6 per cent fewer visits to A&E

- 9 per cent fewer visits to outpatients
- 15 per cent increase in visits to pharmacists
- 17 per cent reduction in number of days off work
- 6 per cent increase in people using health information
- 30 per cent increase in people feeling better prepared for consultations.

*The evaluation found a high rate of satisfaction – people felt the course gave them the skills to be a better self-manager, that they were more confident in managing their illness and that they felt more in control of their condition. Participants listed up to nine self-management skills they would continue to use and listed post course goals. People felt more confident/positive, had a sense of achievement and greater self-acceptance. They felt more able to manage, to set goals and to deal with barriers, they had taken on healthy eating and exercise and had re-learned lost skills. One person said they felt able to overcome depression, another said 'I now have a reason to leave the house.' (Monkhouse, 2005)*

*Previous participants expressed the desire to form a support group and now bi-annual reunions are held with the coordinator from the Greenwich TPCT supporting as required (for example organising suitable venue, contacting past participants).*

- 📖 Organisations offering the courses can provide leaderships by appointing staff coordinating the program (for example, senior trainers, coordinators) that also live with chronic illness.

*The Greenwich TPCT has written the health condition into the job description. This not only provides support and encouragement to people taking the course and lay trainers but also is also helpful in 'selling' the idea of lay led training for self-management of chronic disease to other health professionals. The 'peer' component is very important to recruitment.*

*They now run courses in collaboration with local GP practices - the GP practice identifies patients interested in the course and provides the venue and refreshments.*

- 📖 The successful engagement of other health professionals to see the value of the program and recommend it to patients requires input from clients who have been through the course.

*Greenwich TPCT found that when GPs and other health professionals heard participants from the course talk about the impact it had on their life, there was wider interest in the course throughout the community as the availability of paper information spread and referrals/recommendations from other health organisations in the community increased.*

- 📖 The physical environment is very important in creating the right environment for providing information and encouraging clients to provide their views about the care they receive in a health care setting.

*A suitable environment that is inviting and makes consumers feel comfortable is the first step in engaging clients who require information, advice or want to make a complaint. Variations across the NHS sites visited during this fellowship demonstrated quite clearly the levels of priority that were afforded certain elements of the NHS policy on patient and public involvement. For example, Greenwich TPCT, while highly successful with the EPP programs, were unable to provide access to the Patient Advice and Liaison Service during my visit as the single staff member was on holiday – so clients did not have access to the service for the duration of that absence. The environment confirmed the resources allocated to PALS were limited as the PALS area was a small room without windows, with a table and four chairs in the middle surrounded by file cabinets, boxes of printed material and in one corner a large fridge. This environment was not conducive to the mandate of PALS and clearly neither was it the workspace for the lone staff member. This is of particular concern in terms of effectiveness of the service.*



A Patient Advice and Liaison Service can enhance what should already occur within an organisation that embraces a person centred approach to care.

*The role PALS staff play is multifaceted. They are information providers, listeners, messengers, problem solvers, and mediators, provide assistance and support. PALS do differ considerably across Trusts by virtue of resources. PALS staff recognised that issue themselves – it is most evident when they get calls from patients who have already been in touch with another PALS but have not been able to resolve their issue or received satisfactory responses.*

*The majority of patient inquiries related to information requests, complaints or practical assistance for basic issues like making an appointment with a GP. The organisation does benefit from having PALS. Julianne Meyer, Professor of Nursing at St Bartholomew's, completed a longitudinal study of PALS services in London<sup>1</sup>. Her work indicates that:*

- *PALS is better placed to provide a wider, more comprehensive range of information than any individual program or service*
- *PALS is better able to provide adequate attention to the clients than program/service staff that clearly have other duties and responsibilities.*
- *PALS can provide representation of service users to programs and services and ensure that the client's voice is heard. They also offer an alternative route of complaint for clients rather than directly to the service involved.*
- *PALS can provide feedback to service providers that may inform service development and/or delivery.*

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<sup>1</sup> This work has since been published. See Abbott, S., Meyer, J., Bentley, J. and Lanceley, A. 2006. Patient Advice and Liaison Services: strengthening the voices of individual service users in health care organisations. *Health Expectations*, Volume 9: 138-147

*Essentially, PALS performs a role that makes it easier for service users to get information, resolve concerns or issues and provides opportunities for individual consumers to have a voice.*

## **Suitability to own practice and Victorian healthcare system**

As noted previously, a similar program piloted at Northern Health demonstrated the importance of a peer led program but had limited success in recruiting volunteers. The Greenwich approach provides a number of ideas that could be useful to NH in revising their self-management of chronic disease program.

The 'expert patient' is a title that has evoked some concerns, particularly with health professionals and while the program is named differently in Victoria, it is perhaps worthwhile considering that any program that aims to develop confidence and skills so that the client can work in partnership with the health professional would raise some issues amongst Australian health professionals. Shaw and Baker (2006) report that:

*'A survey by the pharmaceutical industry body reported that only 21% of doctors were in favour of the government's proposals on the expert patient; 58% predicted an increase in the workload of general practitioners; 42% believed it would increase NHS costs; and only 12% thought it would improve relationships between doctors and patients. A more recent MORI survey of health professionals found that 63% of doctors think that in the long run better informed patients will require more of their time—a rather higher proportion than nurses (48%) but less than pharmacists (76%). For these anxious and overworked medics, the expert patient is the demanding patient, the unreasonable patient, the time consuming patient, or the patient who knows it all.'*

So of particular importance is to ensure that health professionals understand the self-management program and its benefits to both clients and those providing health care to them.

The Patient Advice and Liaison Service within healthcare organisations have the potential to consolidate the commitment of health services to consumer involvement and participation at a particular level. While all health services have a complaints procedure and, like the NHS, existing systems for providing information, a dedicated service can serve similar functions identified in this report that would improve links between the organisation and service users and benefit both individuals and services. The effectiveness and scope of such a service would also depend on available resources and appropriate approach to providing the service.

## **Lewisham Primary Care Trust / Wells Park Practice**

### ***Patient as Teachers Model***

In early 2000 Lambeth, Southwark and Lewisham Health Authority brought patients drawn from practice lists together in focus groups and asked what, in their experience of heart disease management, had been most helpful. Ten delegates from these groups then met with twenty primary care professionals. The patients provided their views and health professionals involved used the patient panel as a sounding board for their own ideas about how to change services. The patients' views were

incorporated into clinical guidelines. This was the beginning of what became the Patient as Teachers model that has been used with success to develop good practice guidelines and accompanying videos for improving the care of older people in areas such as cardiac care, assessment and stroke care.

### ***Patient Access to Electronic Records (PAERS)***



Patient using kiosk at Wells Park practice

An innovative approach to patient involvement is the Patient Access to Electronic records. The PAERS system consists of two separate units:

- ◆ the Medical Record Viewing and Patient Education Portal Kiosk
- ◆ the Automated Patient Arrival System.

Currently the PAERS systems work with the EMIS medical records system, but work is proceeding to extend this to include other electronic medical record providers. The PAERS system had been designed and developed by clinicians and patients', ensuring it is a robust but simple to use system that presents the data in an accurate but 'patient friendly' format.

Patients see everything in the doctor's record, apart from information about third parties. Results of tests are labelled to show whether they are normal or whether the patient should see the doctor. Dr Fisher stresses that nothing goes on the system that would have frightening implications without talking to the patient first. Patients can print off records and there are plans to allow them to burn the information to an encrypted CD in the future.

The system also helps patients make difficult decisions, for example whether to have surgery. A library of decision aids in the kiosk takes patients through the process and advises them of side effects.

Dr Fisher has set up the Record Access Collaborative (funded by EMIS) to bring together patients, clinicians, IT suppliers and NHS organisations with the aim of making record access more widely available. A group of GP clinics are also involved in a trial of patient access to electronic records via the internet, with a view to expanding nationally.

### **The activities undertaken during the visit**

- ‡ Half day at Kings Fund library examining London Modernisation information specific to older people.
- ‡ Interview with George Howard, Community Services Directorate, London Borough of Lewisham.
- ‡ Site visit to Well Park GP Practice, Sydenham– presentation by Dr Brian Fisher.
- ‡ Interview with Dr Brian Fisher and Dr Lachlan Clark.
- ‡ Interview with three patients using electronic access to records.

### **Key lessons learned**

- 📖 Access to one's own medical records can empower the person to be more involved in the partnership of care by improving the doctor-patient relationship and promote better health management.

*An evaluation of Patient Access to Electronic Records and my own meeting with patients using the system illustrated the following outcomes for patients:*

- ◆ *Helps put pieces of a jigsaw together to understand history of a particular condition.*
- ◆ *Looking at records helps understand why certain conditions re-occur (track causes of condition over time).*
- ◆ *Improves awareness of health condition and highlight importance of dietary changes to improve health.*
- ◆ *Able to pass on information obtained when visiting hospitals.*
- ◆ *Empowered mentally.*
- ◆ *Better prepared for GP consultation – can talk about results, ask for clarification, ask questions and use time more effectively.*
- ◆ *Can clarify or recap on what has gone on in a consultation.*
- ◆ *Feel more of a partner in health care.*
- ◆ *Feel happier having information.*
- ◆ *Can maximise benefit of short amount of time spent in GP appointment.*

- 📖 Patients who are given more information and take part in shared decision-making with doctors have better outcomes and use health services less frequently.


*The patients at the practice interviewed all had a similar view of the system. They confirmed the evaluation findings and made particular mention of how it had improved the relationship with the GP.*

*'I feel like I know more about what's going on and I can ask the doc questions...before I used to get home and think – agh – I should have asked him about this.'*

*'Yes its like you feel more prepared. I like it because it has it so I can hop around and find out what things mean.'*

*They valued the information links that defined terms, provided insight into their medical conditions and that helped them make decisions. The availability of this through the internet was only used by one client interviewed but with success.*

*'I didn't know if I wanted to have my hip done. My neighbour had a shocking time of it and when the doctor told me that my hip would need surgery I got really worried. But I did what he said and had a look at the information. My granddaughter has the box at home and she helped me get into my records from home – that was even better than at the office – and we looked at all the blue bits where it told me more about the operation. The next time I went back I had written down some questions and the doctor told me everything and ...well then I had it done. Its fine now.'*

 The views of older people are an important part of providing health care professionals with a better understanding of a person centred approach to care.

*The Patient as Teacher approach to understanding person centred care provides clear guidelines to health professionals from older people 'in their own words'. Patients offer unique qualities that can enhance the acquisition of skills and change attitudes towards patients. There has been no formal evaluation of this to date but the wider patient and public involvement reviews suggest that the elements of the Patient as Teacher model can be seen to produce successful outcomes for health professionals and consumers.*

*Dr Fisher, a Lewisham GP, was involved in the initial health authority Patients as Teachers experience. He continues to champion this approach and has been involved in the Patients as Teachers project that produced a good practice guide for assessment of older people. Lewisham Council disseminates the video and the good practice guidelines across all services to support a person centred care approach.*

## **Suitability to own practice and Victorian healthcare system**

Patient access to records is already under trial elsewhere in Australia. While individual doctors or practices may be developing this, there is no significant organised effort to facilitate a system like PAERS. Given that GPs in the UK have been the drivers behind the development and implementation of this system, the GP Liaison Units in Victoria may be well placed to assist in facilitating patient access to electronic records more widely.

The Patients as Teachers model for facilitating consumer and community participation and fostering a stronger partnership in care between clients and health professionals would be important in facilitating and sustaining person centred care. While the name, like the 'Expert Patients Program', will likely need revising to better suit the Australian context, the tenets of the model can be effective for improving care. For improving care of older people it is especially pertinent to assessment. The Centre for Applied Gerontology (the specialist ageing and aged care research unit at NH) led the team that developed the Guide for Assessing Older People in Hospitals that was released by the Commonwealth Department of Health and Ageing in 2005 to all hospitals in Australia (Victorian Department of Human Services was the secretariat for this project). Implementation and appropriate use of this document to improve the care of older people in hospitals has been sporadic and no organised effort to effect implementation is yet to materialise. While the Commonwealth has brought out a brochure to inform consumers about appropriate assessment for older people, consumer and community participation has yet to be considered as a way of making a more dynamic contribution to the implementation of the guide. A better understanding of the client's perspective in assessment can establish a more person centred approach to care, which underpins the Guide to assessing older people in hospital.

## **Liverpool, United Kingdom**

### **Royal Liverpool and Broadgreen University (RLBU) Hospitals Trust**



Bev Tabernacle with staff from the Elderly Health Unit, Broadgreen

The RLBU is in the city centre and has over 49 wards and specialist clinical areas providing 963 beds for inpatient care. Sixteen outpatient clinics operate at any one time provided services for over 300,000 outpatients per year. The major acute services are based within the Royal, together with regional and national specialist services in nephrology, renal transplant, renal dialysis, ophthalmology, haematology, bone marrow transplant and vascular surgery. A major expansion of cancer services is planned. Obstetric and gynaecology, paediatrics, community and psychiatry services are provided by other specialist Trusts. Eleven wards make up the Directorate of Specialist Services for Older People with a range of acute, subacute and rehabilitation.

Broadgreen Hospital (BGH) is situated on the outskirts of the city and has 338 beds. It is the main base for the department of medicine for the elderly and rehabilitation, for dermatology, and for routine orthopaedic and general surgery. There is also a renal dialysis unit on the site and it is the home of the Elderly Rehabilitation Unit. Services to outpatients are well established with six or more clinics running concurrently and around 80,000 outpatients per year.

### **Older Peoples Skills Team**

The Older People's Skills Team Project was implemented over a two-year period. The team consisted of a project manager, two 'F' grade sisters and a level 3 health care assistant. At the time of this fellowship visit, the project was in its final write up stage. The aim of the project was to make sustainable changes to the care that older people receive within the trust and improve access and advice from specialist services. The approach involved the team spending approximately three weeks in each ward area across the trust during which time they audited the standards of care for older people, implemented ward based learning, mentored each nurse by working with them and providing feedback, ensured that evidence based practise was embedded in clinical practice and provided education packs as a resource for newly qualified staff, student nurses and agency staff. Base line data was collected by a nursing skills audit, observations of care, reviewing complaints/patient stories and reviewing of progress with Essence of Care (NHS Benchmarks) and Professional Development Plans. Each ward area developed an action plan for improvement, which is reviewed regularly. This was supported by facilitation of Action Learning Sets. The team had revisited each ward area towards the end of the project and re-audited to establish whether sustainable improvements have been made

The Healthcare Commissions Joint Inspection has identified this clinical skills team as a good example of how to challenge ageist practice within a hospital environment in 2005.

### **Older People's Champion Network**

The National Service Framework for Older People (UK) states that every NHS organisation should designate Champions for Older People to lead professional development and to look after patients' interest. Older people's champions are intended to help to ensure whatever the issue under discussion, the needs, wishes and preferences of older people are fully taken into account. The Royal Liverpool Hospital, following the lead from St Helens and Knowsley PCT, expanded the idea of the Older People's Champion to incorporate a network across the Trust. The current Champions Network was developed in 2001 and has approximately 100 members representing different grades and professions from within the Trust, the Patient and Advice Liaison Service, Age Concern and Patient's Forum.

### **The activities undertaken during the visit**

- ‡ Two-day site visit to Royal Liverpool Hospital.
- ‡ One day visit to Broadgreen Elderly Health Unit.
- ‡ Interview with Deborah Morris, Director Specialist service for older people.
- ‡ Meeting with Clinical Skills team.
- ‡ Interview with Matron Jeanette Roberts.
- ‡ Meeting with members of the Older People's Champion Network.
- ‡ Interview with Bev Tabernacle, Nurse Consultant for Older People.

## Key lessons learned

- 📖 Participatory observation is an effective component of auditing care of older people, that sets the stage for the approach to culture change when completed by people who have some research training and/or experience.

*For the Older People's Skill Team Project, an audit tool to review patient care, with a standard for each intervention, has been developed. Indicators and criteria were devised from the results. This comprehensive audit is completed for each patient over 50 years of age and draws information from three areas; documentation, observations of care and questions to patient, carer and staff.*

*Project staff doing the initial observations did not have appropriate research skills and initial observations were done inappropriately. Provided with training, project staff moved to participatory observations – that is observations were made by project staff working with ward staff on a shift. This also provided the opportunity for project staff to develop a rapport with ward staff.*

- 📖 Action plans to address audit issues relating to the care of older people should be developed by those with a comprehensive understanding of care for older people.

*The Skills Team Project approach called for ward managers to prioritise three key areas for their ward from the audit. The action plan was to be developed based on elements that scored less than 90 per cent (for example, KPIs). However, not one ward manager responded in the pilot. The team identified situational issues such as too much going on (for example, multiple audits, work loads) and not enough familiarity with care of older people as the reason for this lack of response.*

*This issue was addressed by having a team member work with the ward manager to develop the action plan. Over the life of the project the hospital has now moved to only one audit tool specific to person centred care. Mentoring proformas also identify areas of development for personal development plans.*

- 📖 Culture change and skills improvement is more effective when training and support is offered in a practical application within a mentoring framework.

*Once the audit was completed on a ward and an action plan developed, project staff would work with ward staff on improving skills, facilitating a better understanding of care of older people and incorporating a person centred approach to care. The evaluation showed that working on the wards with staff reaped better results than the developments of an action plan and education alone. Results showed better compliance with basic care in areas such as continence, manual handling and nutrition. There was more awareness of and adoption of care pathways (for example, continence, stroke) and falls assessment. The one-to-one mentoring approach was considered crucial in the successful implementation and sustainability of person centred approach to care.*

- 📖 The engagement of older people in all aspects of service planning and delivery can be facilitated through the development of an Older People's Champion Network throughout a health service organisation.

*Champions see an important part of their role to keep older people in the minds of the people involved in planning – for instance just asking 'what impact might these proposals have on older people?'*

- 📖 An Older People's Champion Network is a vehicle for creating awareness of issues that impact on the care of older people amongst clinical and administrative staff across an organisation.

*One of the major factors in raising awareness is that health professionals working in the Trust that are Network members are able to engage their colleagues in daily practice as appropriate.*

*Activities of the network are widely publicised throughout the organisation to encourage staff, patients and visitors to think about the issues concerning older people and facilitate a better understanding of the network.*

- 📖 Older People's Champion Networks are more successful when supported by a key member of staff from the broader health service organisation to provide, at a minimum, secretariat style support (for example, organising meetings, point of contact).

*The National Audit indicated that across the country where Champion Networks had been developed, the key to success was to have a designated staff member responsible for supporting the group at a fundamental level. At the RBLU this is the Nurse Consultant for Older People who acts as the coordinator of the Network. This also facilitated other key elements that research found to be lacking elsewhere. Where research commissioned by Better Government for Older People (Manthorpe, 2004) found that champions who took on the role often found it difficult to give enough time, that many had not received a job description or had feedback on their activities as champions, RBLU addressed these issues in the development of their network, using the 'Toolkit for older people's champions' (2004) as a guide.*

- 📖 Older People's Champion Networks provide an ongoing forum for health professionals and older people to work together to improve the care of older people.

*The RLBU has expanded the initial concept of the Older People's Champion put forward by the National Service Framework and have developed the network by having champions that incorporate clinical, executive and staff representatives across all departments and older people as well. The Older People's Champion Network was acknowledged in a recent Healthcare Commission review as being the only active network currently operating in Liverpool. This review praised the Network for the role it has been playing in improving the care of older people. The key components of the success were identified as:*

- *Champions at RLBU work together and use their influence to represent the interests of older people.*

- *There is considerable support amongst champions to ensure that health and social care systems collaborate to address issues concerning older people.*
- *The way in which champions, who are not older people (for example, clinicians, staff members) give voice to issues that appropriately reflects the views, concerns and preferences of older people.*

### **Suitability to own practice and Victorian healthcare system**

Northern Health has had responsibility for developing and delivering the Enhancing Practice Education to improve the care of older people across Victoria. This is currently still being completed across the state. In addition, the Guide for Assessing Older People in Hospitals (CAG/NH led development) has yet to be appropriately put into practice as intended. It is envisaged that both the Older People's Skill Team model and the Older People's Champion Network can build on activities within Northern Health and across Victoria and make a strong contribution in improving the care of older people.

## ***Dundee, Scotland***

### ***University of Dundee/Dorothy Dobson's Over 60's Exercise Class***



St Andrews class

Dorothy Dobson began her exercise classes in Dundee over 20 years ago with a view to trialling safe, appropriate, sensible exercise for people growing older. With fifteen hundred older people attending every week, Professor Marion McMurdo, Chair of Ageing and Health and Dorothy Dobson co-founded a company, DD Developments to expand outside of Dundee. Specialist exercise classes for over 60's, based on the intensively evaluated Dundee University class led by Miss Dorothy Dobson have been established throughout the UK. Profits are pledged to support research into ageing and health.

Each of the exercise classes last for 45 minutes and comprise predominantly weight-bearing exercise performed to music, led by an instructor from a podium in the centre of the hall. There is a warm-up period of 5-10 minutes at the start and a cool-down period at the end of each session. The format of the class contains elements of endurance, muscle strengthening and stretching. Optional refreshments follow the class.

## The activities undertaken during the visit

- ‡ Site visit to observe St Andrews Exercise Class; interviews with leader and members of the class.
- ‡ Day with Dorothy Dobson at University offices, examining paper work relating to the expansion across the UK and interview with Dorothy.
- ‡ Interview with Professor McMurdo, co-founder and researcher.
- ‡ Site visit to observe Aberdeen Exercise Class; interviews with leader and members of the class.
- ‡ Site visit to observe Dundee Exercise Class – conversations with members.

## Key lessons learned

- 📖 Transfer of a successful model of exercise for over 60's requires careful consideration of location, leader and marketing.

*In identifying the key factors in transferring the success of her Dundee classes to other areas, Dorothy Dobson highlighted the need to take into consideration the local area idiosyncrasies and issues such as transport, access to venue, suitability of venue, locals views on venues. In addition, a major factor in success is the choice of leader. The exercise class is based on participants copying the class leader so there is usually a podium or raised platform for the leader in the centre of the room so that all participants can clearly see the exercise movements.*

*Equally as important to participants, if not more so, are the social aspects of the class. Hence, in considering the suitability of the venue, the environment should be conducive to exercise for a larger group, seating availability for resting and after class refreshments. Participants in Dundee, Aberdeen and St Andrews classes expressed the importance of socialising, being able to exercise at their own pace, and the music.*


*The music is also very important to the participants and Dorothy Dobson provides the play list to all leaders weekly. While it is a broad mix of music, participants expect particular types of music to be included.*

*Because it is made clear to new participants and reinforced by the general atmosphere of the class, participants feel very comfortable exercising to their own pace. The participant decides what they exercise they do.*


*The marketing of the classes in new locations begins several weeks before they commence. Local newspapers, community networks, health centres and GP practices, age-specific housing communities, social clubs and even neighbourhood leaflet drops are all part of the distribution of information. The first class is always a coffee morning where prospective participants can come along, meet with the leader and are introduced to the concept through information and videos of other classes. DD Developments provide support throughout the marketing process, including outlining a pre-opening schedule with*

*tasks to maximise exposure. Dorothy Dobson often does interviews for local newspapers and radio during the lead-time. Key messages in the marketing include information about how the exercise classes have been developed out of medical research, testimonials from class participants elsewhere and the social and physical benefits of attending the classes.*

*A great deal of the appeal of the classes is that they are community based and this becomes more salient in classes over time as a reason why people continue to attend. Participants come to a local venue and are with older people like themselves who live in the community – many classes raise money for local charities or community needs, hold social functions and so on. For example, during the visit for this project, the St Andrews class was organising a luncheon trip for participants to a country venue and selling raffle tickets to raise money for a local community children's group.*

-  Older people are more likely to continue attendance at classes if leader is a professional.

*The leader of all classes is a qualified professional (for example, a physiotherapist) that received further training in Dundee specific to this model. Participants in the classes across the country have identified this as an important reason why they attend these particular classes. Participants interviewed in Dundee, Aberdeen and St Andrews classes confirm that the leader was very important as they form a strong relationship with the leader over time. They like the fact that the person is a professional but also that they receive specific training at Dundee.*

-  The development of the exercise program has been guided by research and evaluation over time to maximise the benefits to participants.

*This method of exercise has evolved with input from research by members of the medical staff from Dundee University and Ninewells Hospital. Exercises have been included or deleted as the knowledge has increased. Professor McMurdo has published extensively on this research.*

*Older people with poorly responsive depressive disorder should be encouraged to attend group exercise activities (Mathers et al, 2000).*

*It is important to dispel the myth that the main benefit of exercise is fitness, which for older people is often an irrelevant concept. Rather, people are more readily motivated to participate in exercise if they can appreciate the benefits to their own health, such as maintaining function, limiting the morbidity and mortality from chronic disease (McMurdo, 1997).*

## **Suitability to own practice and Victorian healthcare system**

Bundoora Extended Care Centre (BECC) has recently appointed a Health Promotion Coordinator to further enhance health promotion for older clients. This position sits within the Community Liaison Unit to ensure appropriate community and consumer participation. As BECC provides a

range of rehabilitation and ambulatory services, it is envisaged that it is well placed to examine the potential for this type of exercise class in the local area. Through its links with other Centres for Promoting Health Independence throughout Victoria there is the potential to widen the scope across the state where the need is evident. This would be timely in the light of the development of Commonwealth work on specific guidelines for physical activity for older people. We would also hope to involve the GPLU to facilitate learning and links with GPs about exercise classes for over 60's model as previous research has found that older people are more likely to try organised classes if prescribed or recommended by their own doctor. There is already a trained leader in Australia located in Queensland and runs successful classes in her local area.

## **Quebec, Canada**

### **Sainte Anne's de Bellevue**

#### **Ste. Anne's Veterans Hospital**

Ste. Anne's Hospital is the only federal hospital remaining in Canada. It is the last hospital administered by the Department of Veterans Affairs (DVA). With over five hundred residents, the majority of which are men, with an average age of 86 and more than 40 per cent with dysphagia, the DVA has made significant investment in research and quality improvement to address the needs of the residents of Ste. Anne's.

#### **Reconstituted Food Program**

Since 1993, Ste. Anne's Hospital has been providing dysphagic (difficulty chewing and swallowing) residents with a reconstituted food program. This program is unique and greatly contributes to stimulating the appetite of dysphagic residents who are relegated to eating purees and thickened liquids. Such a diet often leads to malnutrition and dehydration, thus making residents more vulnerable to infections. Ste. Anne's Hospital has opted to nourish and hydrate its dysphagic residents in the most normal way, that is, orally, with foods the texture and viscosity of which have been modified to make them more appetizing, recognizable and familiar, but also safer and easier to eat. Quality criteria for these specialised foods, including appearance and nutritional value, must be equivalent or superior to their normal counterparts. The reconstituted meals resemble their normal counterparts so closely that their modified texture is only apparent when tasted. The assortment of foods available include forty or so solid modified texture foods and as many liquids and beverages of controlled viscosity, which enables Ste. Anne's Hospital to provide its dysphagic patients with an exceptionally varied menu that is virtually identical to the regular menu. This program and its technology have won numerous awards in Canada.



Ste. Anne's Research Dietician (centre) with Insitut Universitaire staff

## The activities undertaken during the visit

- ♀ Site visit Ste. Anne's.
- ♀ Site visit to production kitchen.
- ♀ Site visit to Institut Universitaire de Gériatrie de Montréal.
- ♀ Interviews with research dietitians.
- ♀ Interview with Coordinator of Clinical Programs.
- ♀ Interviews with Director of Research, Ste. Anne's, and DVA Research Directorate, Charlottetown.

## Key lessons learned

- 📖 Research based food technology is an important part of best practice for dysphagia treatment that can put the joy back into eating.

*Based on eleven years research, the food provided to Ste. Anne's residents with dysphagia have, as they say, put the joy back into eating. The research and development program commenced in 1993 in response to issues relating to weight loss and nutrition for residents with dysphagia. The aim of the research was to develop foods efficient in improving health. They began by standardising the products – quantifying the texture of liquids and solids. They standardised the diet prescription for clinical intervention also. By 1998 they had the proof of the concept of reconstituted food and a randomised control trial of the Technology Transfer Project and creation of the Prophagia Company took place in 2000.*

*There are two quantified adapted textures (minced and puréed). The texture profiles developed incorporate firmness, adhesiveness, cohesion and springiness. A Safe Swallowing Texture Index (SSTI) has thereby been developed. All this work is patented. They have linked with a commercial partner in Canada and are about to launch the products across Canada. Forty-two main entrees (meats, fish, poultry and pasta – minced and puréed), ten vegetables (raw and cooked – puréed), nine cakes and six fruits (puréed) and fifteen varieties of thickened beverages (nectar, honey and pudding consistencies for each) including soft drinks, coffee, tea and on special occasions beer and wine.<sup>2</sup>*

*The results of the randomised control trial showed:*

- *weight loss stopped in most residents*
- *residents with Parkinson's disease and dementia returned to normal weight after nine months*
- *body mass index for control group remained at 21.2 over a twelve-week period compared to the group receiving Epikura foods, which went from 22 to 24.50 in the same time period.*

*The Epikura line of foods offers a balanced and varied diet to dysphagic clients, competitive prices, uses fresh ingredients and is individually portioned.*

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<sup>2</sup> See appendix 1 for photographs and graph of results.

*Most telling is the remarks by residents who have been eating the reconstituted food.*

*'I can tell what I'm eating now. Before it was okay but it was mush in a bowl. I had chicken, beans and potatoes today.'*

*One lady I spoke to cried as she told me as she ate her salad aspic with tomato slices and French vinaigrette:*

*'I hadn't had salad in eleven years –it's just so wonderful.'*

*All residents interviewed indicated that they really looked forward to mealtime now. They would eat in the dining room whereas many before ate in their rooms. Others indicated that they noticed the difference in weight:*

*'I had to get my daughter to let out my pants after a while,' one man commented with a laugh.*

*Hospital staff indicated that there has been a significant decrease in the use of food supplements since the introduction of this food technology.*



*Dementia friendly physical environments can be undermined by the inclusion of features seen as necessary in the medical model of care of older people.*

*Although this was not part of my original project, Ste. Anne's was just completing building on a new dementia care unit for 129 residents. Given that they had already implemented a person centred approach to care within the original hospital building (a very traditional old hospital physical design) with success, it seemed appropriate to tour the site.*

*What is of particular interest here is that although there was wide consultation across the hospital, particular decisions had been made that were not in keeping with a dementia friendly physical environment. The building was designed with the idea of making a homelike environment and was a two-storey cluster type design with sections of nine or ten private rooms off a main public area. The public area contained an activity kitchen as a focal point but would not be used to prepare or even provide service for meals. There was lots of natural light and access to secure outdoor areas. However, three significant components were included that are in conflict with the research evidence. They did not have carpet at all, not even in the bedrooms. Although the flooring was non-slip it seemed to generate glare. I was advised that carpet had been excluded as it was too expensive to upkeep. Although they were going to maintain the personalisation of bedrooms in the resident's rooms, as was the case in the main hospital, they had also maintained the hospital lighting over the bed. Hence clients would not be able to arrange their room the way they would like because of fixed inappropriate lighting. I was advised that clinical staff had insisted on this type of lighting for wound care. Finally, they had included a nursing station in each of the sections. Although it was not the central point in the public area, it completed the 'hospital atmosphere' of the entire building rather than the homelike environment they were hoping to*

*create. Discussions with other members of staff indicated that there had been considerable opposition to all three of these elements.*



A snoezelen cart can contribute to a multi-sensory program to enhance quality of life.

*Because of the physical environment of the original hospital building at Ste. Anne's and the number of residents, staff developed a snoezelen cart to bring the multi-sensory experience to more residents effectively. The assessment of a resident incorporates capacities and preferences, restrictions and aversions across physical/motor function, cognitive function, perceptual, communication, senses and proprioceptor senses (somatique – muscles/skin), vibratory (bones and articulation), vestibular (position of body in space, balance, standing and walking) and thermal (temperature). This assessment informs the action plan development for a range of multi-sensory activities and the day/time best completed. The multi-sensory activities can be done in the resident's room or any area of the hospital that is appropriate because it is all contained on the cart.*

### **Suitability to own practice and Victorian healthcare system**

The snoezelen cart would be an excellent way of bringing the multi-sensory activities to clients in hospital settings. It has the potential to service the community settings as well. Nursing homes who are unable to have a dedicated snoezelen room could easily develop a cart or share a cart with other local nursing homes.

The reconstituted food is by far the most exciting innovation in the treatment of dysphagia and represents a giant leap forward in bringing food to the forefront of health care considerations. Dysphagic older people, whether in residential care, hospital, or in the community can benefit from this innovation. It is not just for older people – people of any age with swallowing difficulties would be able to enjoy a wide variety of food and drink and maintain nutrition. Two patents exist for the method of preparing the food and for quantifying the texture of the foods but they are seeking partners to ensure its development and distribution. Therefore it has huge potential benefits for not only the Victorian healthcare system but across Australia. Options for its Australian introduction will be pursued vigorously.

## ***St Catharines, Ontario, Canada***

### ***T. Roy Adams Regional Centre for Dementia Care***

The Adams Centre is operated by the Regional Municipality of Niagara, through its senior's services (Community Services Department). The Adams Centre is comprised of two distinct components: a respite care centre and a complex care centre. Residents across the Niagara Region can access these services. It was developed in response to family members who cited the need for improved and specialised respite care and in response to a Niagara District Health Council needs assessment.

The respite centre is like a small bungalow with an appearance similar to the homes in the adjacent subdivision. It has two symmetrically designed areas of four bedrooms each with an adjoining living room, kitchen and dining room and bathing suite. There is also a laundry room and garden room to assist in providing meaningful activities.

The complex care centre is also designed on a small residential scale and has two symmetrically designed areas: one with eight bedrooms and the other with nine bedrooms, each area with a dining room, living room and bathing suite.

To make these small scale facilities feasible, they have been connected to a larger existing residential care facility from which the administrative and service infrastructure is provided. All nursing staff dedicated to the centre have specialised dementia care training and experience and staffing levels are slightly higher to reflect the specialised care requirements of clients and residents.



T. Roy Adams Respite Centre

### **The activities undertake during the visit**

- ‡ Site visit to the respite and complex care centres – half day participating in activities, including lunch.
- ‡ Interview with Dominic Ventresca, Director Seniors Services.
- ‡ Interviews with staff of centres.

- ‡ Meeting with residents of centres.
- ‡ Meeting with volunteers and family members.

## Key lessons learned

- 📖 A model of dementia care that provides respite, assessment and intervention in a dementia friendly physical and social environment has significant benefits to the clients, organisation and community.

*Staff, residents and family members involved with the centre clearly articulated the benefits of the environment.*

*'I drive up in the morning and its just like going to a friend's house,' one husband remarked, 'Betty is so much better since we've been coming here. When she has a funny turn at home now I know what to do to make her feel happy again. It's been a blessing.'*

*While no formal evaluation has yet been completed, initial internal reviews indicate that there are clear benefits. There is now day respite available, which is enabling clients to stay at home longer as carers are getting better support. This support is not only in terms of the respite from care itself but also because the centre provides education and practical advice around dealing with behavioural and other issues that may arise. Similarly, the complex care centre is filling a gap in service provision that has seen significant benefits. Nursing homes in the region can refer residents to the centre when they are experiencing difficulties and are unable to provide appropriate care. The client is assessed and appropriate interventions are put in place. Sometimes a short stay can address the issues but again, support is provided to the organisation through education and practical advice. A stay at the centre can be an interim situation while awaiting appropriate residential care or if family carers and/or client require longer respite. There is a significant body of research evidence to support the anecdotal evidence provided through interviews during this project that illustrates the benefits of homelike, dementia friendly physical and social environments.*

- 📖 Respite and complex care short stay models that incorporate the transfer of the knowledge, skills and interventions that are unique to the care of the resident to associated carers (whether formal or informal) enhance practice across settings.

*This model has some particularly important features that make it innovative in dementia care. The Respite Centre works in partnership with others to bridge the transitions for the individual and their caregiver from their own home to the facility and back to the community. It does this by:*

- *Optimising the functioning of the individual during the respite time with activities that are purposeful, meaningful and appropriate – the aim being to develop an individualised program to maintain and enhance the individuals' functional level.*
- *Offers respite to caregivers and support to families in their decision-making.*

- *Involves carers in the care process, establishing care needs and problem solving with the staff.*
- *Informs, educates and raises awareness of consumers and other service providers about respite care.*

*The Complex Care Centre works is providing comprehensive and complete assessment to better manage the complex needs of clients, particularly when expressed through behaviours. The intention is to incorporate the program into the continuum of health care service to effectively meet the needs of older people experiencing dementia and specifically serves people with behaviours that are not met by current services. Particular attention is paid to passing on the knowledge and understanding so an important part of the work done in this centre is to transfer to associated care providers the knowledge, skills and interventions that are unique to the care of the resident.*

### **Suitability to own practice and Victorian healthcare system**

I have recently led the team that developed a resource for creating dementia friendly physical and social environments that brings together research evidence and best practice understanding to support those providing residential care in Victoria. The Department of Human Services commissioned this resource to be distributed throughout the state. This model provides a very innovative approach to providing respite and complex care that would enhance dementia care in Victoria. Of particular significance is that this model, through respite, assessment and intervention in a dementia friendly physical and social environment, provides support to family carers and to staff of organisations and therefore is able to enhance care across setting through the education and practical advice.

## ***Tupelo, Mississippi, United States***

### **The healthcare organisation**

#### ***Mississippi Methodist Seniors Service/Traceway Green Houses®***

Mississippi Methodist Seniors Service offers a range of care options in the local community. At the Traceway location, older people can access retirement village accommodation, assisted living units, traditional nursing home care and Green House® living environments. The Tupelo Green House® project was part of a plan to upgrade its 140 bed Cedars Health Centre, a traditional nursing home. The first of its kind in the US, the

twelve houses are now fully occupied.



Rene (Shabaz) cooking lunch

A Green House® is a self-contained dwelling for eight to twelve people that is designed to look like a private home or apartment in the surrounding community. Each person who lives in a Green House® has their own bedroom and bathroom. Each Green House® has a central hearth with an adjacent open kitchen and dining area, and short halls with access to the hearth. There is a common eating area and living room area, easily accessible from the private bedrooms. Family members, friends and workers are welcome to join residents at mealtimes and during other activities. Like any home, visitors and

visiting staff ring the doorbell for entry. A separate clinical support team includes nurses, social workers, therapists, medical personnel, nutritionists and pharmacists. One nurse from the clinical team serves residents in two to four houses and other clinical professionals visit regularly and as individual residents require.

### **The activities undertaken during the visit**

- ‡ Meeting with Ellen Bartoldus, Project Guide, New York City.

- ‡ Conference call with Robert Jenkins, Deputy Director NCB Development Corporation, Washington.
- ‡ Two-day site visit to Green House® Project in Tupelo, Mississippi.
- ‡ Interviews with Director and Project Guide, Mississippi Methodist Seniors Service.
- ‡ Conversations with residents in two of the ten Green Houses® in Tupelo.
- ‡ Meeting with three relatives of residents.



Green Houses

### Key lessons learned

- 📖 The small home-like environment can be cost effective in providing appropriate care in the residential setting because it shifts costs away from supporting the institution and towards the direct care needs of the resident.

*This not for profit organisation finds the cost of providing the small home-like environments with the specific model of care comparable in cost to their own 120 bed traditional nursing home. Although the staff to resident ratio is higher, savings have been made by streamlining jobs and shifting resources. Separate departments to deliver housekeeping, dietary and personal care services are not required as the up-skilled Certified Nursing Assistants known as 'shahbaz' manage the household. The use of food supplements and incontinence products has been reduced and costly staff turnover has been significantly reduced. So, while direct care staff costs increased, clinical staff, activities staff and building and grounds costs were similar to the nursing home but all other costs dropped significantly.*

- 📖 Education and support of staff and family that addresses professional, cultural and social issues relating to a model of care that focuses on the resident is essential.

*Nurses were concerned about the ability of shahbaz to manage the household and maintain appropriate quality of care for elders and raised issues relating to clinical care. They were also concerned about their own position within the organisation with the flattened hierarchy of the Green House®. Management provided support and education to nurses and demonstrated that this model enabled them to return to 'nursing' that utilised their knowledge and skills much more effectively and professionally.*

*Similarly, family members voiced initial concerns about the absence of in-house nursing and other clinical staff. Management provided education and support to provide families with a better understanding of the philosophy of care and the need to provide the full spectrum of home-like environment that did not include a central nurses station and the presence of clinicians at all times. However, once the elders moved into the first couple of houses and family and staff saw immediate positive impact on the residents, the majority of family members concerns dissipated.*



The empowerment of direct care staff is essential for sustaining person centred care.

*The flattened bureaucracy within the organisation empowers direct care staff to better respond to the needs of the individual. As the crucial agents of change, these staff members blend the roles of caregiver, homemaker and friend. Staff work as a self managed team, rotating duties, each taking a turn quarterly as:*

- *team coordinator (liaising between team and families, volunteers, community members and other members of staff including clinical support)*
- *food coordinator (organising weekly food menu-planning meetings, ordering food, monitoring freshness and adequacy of supply, ensuring compliance with rules governing kitchen cleanliness, food temperatures etc)*
- *housekeeping coordinator (monitors cleaning, orders supplies and recording information, laundering of household items and elders' personal items)*
- *scheduling coordinator (creates schedule in collaboration that provides adequate coverage, while meeting requests for time off and are first point of contact if sick or unable to work)*
- *care coordinator (monitoring the team's compliance with care plans and their effectiveness at meeting elders' needs – ensures that care has been provided and documented).*

*Shahbaz at Tupelo had developed a deep understanding of the elders in their care. Some relationships are stronger than others and this is recognised amongst the shahbazin in every day life, as the most appropriate person takes the lead in responding to a particular resident's need at any point in time. When asked what was the most challenging part of the job, one shahbazin replied – 'nothing really – everything is a joy' and she described the best part of her job as 'the elders – my friends'.*

- 📖 Residential care settings should be designed to be a person's home not a nursing facility.

*A Green House® is designed to be a person's home for life, and their ability to remain in a Green House® is not dependent on their medical condition. The clinical care and activities are organised around the needs of the individuals who live there. The people who work and live in a Green House® collaborate to create a daily routine that meets the individual needs, much as they did in their own homes. If residents want to be involved in cooking, preparing snacks, light housekeeping and laundry or gardening, they are supported to do so. There is no institutional routine in terms of medical care, allowing residents to be more independent.*

*Evaluation by Dr Rosalie Kane, University of Minnesota shows:*

- *high satisfaction levels from residents, family and staff*
- *fewer complaints at state level*
- *no unexplained weight loss, and almost no nutritional supplement use*
- *less decline in activities of daily living (ADL)*
- *staff turnover of less than ten percent*
- *no transfer-related back injuries in elders or staff*
- *less prevalence of depression*
- *less incontinence without a toileting plan*
- *less use of anti-psychotics without a relevant diagnosis.*

*With the focus on home design, it allows buildings to be designed as best fit for any location. For example, while the detached house design on a street suits the Tupelo location, in Manhattan apartment living is more appropriate and so design would reflect that type.*

## **Suitability to own practice and Victorian healthcare system**

I have recently led the team that developed a resource for creating dementia friendly physical and social environments that brings together research evidence and best practice understanding to support those providing residential care in Victoria. The Department of Human Services commissioned this resource to be distributed throughout the state. The Green Houses® provide a good example of excellence in residential care that provides evidence to counter many of the arguments put forward regarding the feasibility of small, homelike environments. As the notion of the Green House® is the flexibility of the model to be developed as appropriate for location, its adaptability for the Victorian context is highly practicable.

## ***Salem, Oregon, United States***

### ***NorthWest Senior & Disability Services (NWSDS)***

NWSDS is a local intergovernmental agency in Oregon that was formed by Marion, Polk and Yamhill counties in 1982 and expanded in 2005 to include Clatsop and Tillamook counties. As the designated Area Agency on Aging and Disability Services for Clatsop, Marion, Polk, Tillamook and Yamhill counties, NWSDS develops and maintains a comprehensive and coordinated service system to meet the needs of seniors and people with disabilities. Our approach to these responsibilities is reflected in the agency's mission statement – to assist older persons and people with disabilities in making and implementing choices that maximise their independence and quality of life – and the agency's core values of customer service, professionalism and positive attitudes. NWSDS is governed by a Board of Directors, which is comprised of five county commissioners, one each from Clatsop, Marion, Polk, Tillamook and Yamhill counties. The Board relies heavily upon the recommendations and wisdom of a board-appointed 27 member Senior Advisory Council and a 15 member Disability Services Advisory Council.

The services coordinated and provided by NWSDS include, but are not limited to: information and assistance; case management; eligibility determination for Medicaid, general assistance and food stamp entitlement programs; adult protective services; licensing of adult foster care homes; pre-nursing home admission assessments; home-delivered meals and family caregiver support. Additionally, agency staff authorise and arrange an assortment of long term care services including nursing facility care, residential care, in-home services, respite care, and adult day care programs.

### ***Senior Advisory Council***

The 27 member Senior Advisory Council is made up of older adults (60 years and older), representatives of older adults, local elected officials, persons with leadership experience, representatives from agencies providing services to older adults and the general public. The function of the Advisory Council is to advise the Board of Directors and the Executive Director on the clients to be served by North West Senior and Disability Services, the general welfare of seniors and people with disabilities in the areas service by the agency and on all important matters affecting the operations of the agency, except for matters of personnel administration, staff pay and benefits. Depending on the goals of the council and individual interests, members service on committees that participate in the following types of activities:

- review and make recommendations about agency goals and objectives
- give advice about policy and priorities of the agency as it relates to clients served
- share in the development of new ideas/concepts within the agency
- monitor agency programs

- advocate for care or services needed to improve quality of life of seniors and people with disabilities.



Members of the Seniors Advisory Council

### ***Senior Peer Mental Health Counselling Program***

Available across the state of Oregon, volunteer's work with older adults experiencing life challenges and concerns of growing older, such as depression, adjustment issues from relocation and physical changes, loneliness, retirement, and grief. Senior peer counselling provides confidential, supportive, and personal mentoring.

### **The activities undertaken during the visit**

- ‡ Speaker at the Oregon Gerontology Association Annual Conference.
- ‡ Site visit to NorthWest Senior and Disability Services head office.
- ‡ Attendance at a monthly Council Meeting.
- ‡ Meeting and interviews with council members and NWSDA management.
- ‡ Site visit to the Active Living Centre.
- ‡ Interview with Jim Davis, Associate Professor, Department of Human Sciences, Marylhurst University.
- ‡ Interview with Jeff Lukehart,
- ‡ Meetings with peer counsellors.

## Key lessons learned

- 📖 Organised consumers have significant scope to advocate for health service for older people.

*The Seniors Advisory Councils (SAC) have been developed across Oregon. The SAC for the NorthWest Seniors and Disability Service is actively involved in a range of activities that enhance the quality of care provided to older people in the five counties their service organisation covers.*

*They work at a high level of consumer participation in that they provide input into policy and planning of services. They monitor and review the delivery of services and provide feedback from the community. They act as a conduit between the organisation and the community. An important role is that of advocacy. They provide other community members with information about potential political decisions and their impact on issues relating to the health and social care services for older people. They advocate directly to politicians as individuals (informed through the Council framework) and advise politicians as an organised Council (a subtle distinction because of the lobbying laws).*

*Council members come from all walks of life but have a commitment to ensuring services meet the needs of older people in the community. They are very proud of the outcomes of the Council's work. Many members highlighted the latest achievement – the meals program – providing meals to people over 60 at community locations so that they have the opportunity to socialise with others.*

*Administration support is provided by the organisation and senior executives and support staff attends the Council meeting. The meeting is led by the Chair of the Seniors Advisory Council. He works in collaboration with organisation and other council members to set the agenda. Community members can come to the meetings and present issues. The meetings are dynamic. Members are provided information for discussion and kept informed on policy issues at the Federal and State level. It is a significant investment of time for Council members but many are long serving.*

*Staff members identified the Council as an important link to the community and valued the input and work of the Council highly. Of particular importance was how the Council members were able to take information to the community and in turn feedback into the council from the community. Their role as advocates in the political arena was highly valued.*

- 📖 Peer mental health counselling can be a valuable contribution to the services available to enhance emotional well-being of older people in the community.

*Senior counsellors are not problem solvers, but they are trained volunteers who want to help older people understand and cope with life changes. The aim is to help people remain independent, self-reliant and promote healthy ageing. After an initial in-home assessment by the coordinator, seniors accepted into the program*


*will be matched with a senior counsellor. The person is not obligated to enter the program and they may leave at any time. Meetings between the individual and the counsellor usually occur in the person's home for an hour at a mutually convenient time. The visits may last from a few weeks to a maximum of one year. All conversations are held in the strictest confidence. Counsellors debrief with the coordinator once a month.*

*The counsellors find it very satisfying to be able to provide support to other older people. Several had other volunteer commitments, for example, hospital volunteer driver, and local school library. These volunteers indicated that they wanted to give more back to people and when they found out about the peer-counselling program it appealed to them in that context.*

*'I liked the idea of being able to help someone work through those things that come up in every day life when you are getting on...I'm no expert but I've been pretty lucky with life so I just wanted to do more than just drive people.'*

*All those interviewed found the training generally prepared them for the work they were doing with others and they felt well supported in those instances when they did need additional help and guidance. For example, one counsellor said:*

*'I had visited this guy a few times. I got the feeling there was just something...well...not quite right. I was a bit uncomfortable. I didn't think I was helping so I went to Jeff and talked it through.'*

 Peer counselling needs to be appropriately integrated into a wider service to ensure sustainability.

*This program was running successfully but could just as easily fold next week. The funding was minimal – paying expenses and the salary of the coordinator. The coordinator, a dedicated individual who had developed the program in this area of Oregon, applied for the funding annually. He trained all the counsellors, did the initial assessments on the individuals referred to the program (usually by GPs or other providers – some self-referrals) and he monitored and supported the counsellors. If he decided to move on then there were questions around whether the program would continue.*

*Given its long running success (nearly 15 years), it seemed that it was far too dependent on one individual. This model is not conducive to sustainability or to being valued appropriately within the network of services. The other issue was the lack of appropriately qualified personnel in the area of mental health counselling involved in the program. The coordinator was not a clinician although he did have a PhD in psychology – his background was not in counselling but rather academic and in State government.*

*Academic Jim Davis has reviewed the peer-counselling program and found it to be highly beneficial to older people who had been*

*involved in the program. Most had not required professional mental health services, although the few who did had indicated that they were able to get more out of the professional service because they had been initially involved with a peer counsellor. Generally, people indicated that they felt that they were not alone and were able to use the counsellor as a sounding board. Professor Davis had high praise for the work of the coordinator.*

### **Suitability to own practice and Victorian healthcare system**

The Seniors Advisory Council is a model of community and consumer participation that is more comprehensive than the current Community Advisory Committee's operating at Northern Health. Working with the two committees at NH, it is envisaged that the activities of the SAC may provide additional actions for the strategic plan currently under development.

At the broader level, the Centre for Applied Gerontology will work with community development managers and appropriate government representatives to examine the potential for a State level Seniors Advisory Council.

The Senior Peer Counselling Program in its existing format is not ideally suited for the Victorian context but does provide a basis from which to develop a more appropriate model. The fundamental premise of the model in which older people provide counselling to other older people is certainly an innovative and worthwhile approach to contributing to the mental health service and enhance community participation in that area. This will be further explored with key clinicians and community services at BECC to explore opportunities for further development. CAG will provide support in facilitating this development with assistance in providing information, seeking funding opportunities, proposal writing and liaisons with community networks.

## **Sharing and promoting the project**

### *Presentations*

Oregon Gerontology Association Annual Conference – Guest speaker (Aug 8/06)

Northern Health Community Advisory Committee (Sept 18/06)

Bundoora Extended Care Centre Heads of Department (Oct 17/06)

Whittlesea Aged Services Network (Oct 12/06)

Central Hume Aged Care Forum (TBA)

Dieticians and speech pathologists (Northern Region - TBA)

Additional presentations will be made on request and key organisations will be targeted to offer information.

An abstract has been submitted to the Alzheimer's Association National Conference 2007 to present findings from components relating to translating research into practice around person centred care and dementia friendly physical and social environments.

Other conference and seminar presentations will be considered for other components of the project.

### *Information Access*

All information collected will be housed in the Centre for Applied Gerontology Information Clearing House attached to the BECC Medical Library, which is networked across Northern Health.

Written reports on specific elements of the project will be provided to the appropriate programs and services across Northern Health.

The Centre for Applied Gerontology publishes reports relevant to improving quality of care and quality of life for older people. It is envisaged that CAG will produce a report or reports that highlight the learning's from the project.

## Improving the Victorian healthcare system

It is envisaged that, in collaboration with the Canadian Prophagia team, we will seek ways to introduce the reconstituted food into Australia. We are currently investigating research and development funding opportunities and health research funding opportunities as part of the groundwork for this venture. In the first instance, we are working towards a pilot within Victoria that would involve dietitians. Clinicians within Northern Health have already been contacted and have expressed interest in championing this project within their discipline networks.

The Northern Health Community Advisory Committee has incorporated the Patients as Teachers project model and the 'Older Peoples Champion Network' into their strategic plan. They have instructed me to approach management at Bundoora Extended Care Centre to help facilitate a pilot of the Patient as Teachers for assessment and to support the development of the Champions Network. The Acting General Manager has indicated her support and a meeting is currently being arranged between the General Manager, the Manager of Service Redevelopment, the Community Development Manager, the Volunteers Manager and Deputy Director of the Centre for Applied Gerontology to develop a proposal to the Executive of BECC. It is envisaged that the Champions Network would be an all of Northern Health network and the proposal developed at the BECC campus would be presented to the board through the NH Community Advisory Committee.

The Centre for Applied Gerontology will work with managers of programs and/or services across Northern Health as appropriate to facilitate components of the project that will improve person centred care for older people. The Older People's Skills Project will be promoted as a model for assisting with the implementation of the *Guide for Assessing Older People in Hospitals*, and for improving quality of care for older people. The role of the Centre for Applied Gerontology will be to seek funding sources, assist in writing proposals and supporting managers in developing and implementing the project. Key contacts for components of this fellowship will be provided as required to promote ongoing links to clinicians at Northern Health with overseas colleagues.

There is significant information gathered for this project that will be made available through the Centre for Applied Gerontology Aged Care Information Clearing House housed in the Bundoora Extended Care Centre Medical Library.

## Project accountability requirements

### ***Any variations to the project methods and processes***

The original plan identified Baycrest Geriatric Centre in Toronto as a site where the translation of research into practice was to be investigated. Despite email confirmation, on arrival there were no arrangements in place and key staff were unavailable. Alternate arrangements to visit the T. Roy Adams Centre for Dementia Care in Ste. Catharines, Ontario were put into place through local contacts and this is reported on in this document.

## Supporting information

### ***Bundoora Extended Care Centre Medical Library***

- ❖ Patient Access to Electronic Medical Record and Automatic Arrival System. PAERS Ltd. 2004
- ❖ Fisher, B., Fitton, R., Poirier, C. and Stables, D. *Patient Record Access – The Time Has Come*. 2005.
- ❖ Parr, C., Pound, C. Byng, S., Moss, B., Long, B. And Firenza, C. *The Stroke and Aphasia Handbook*. London: Connect Press. 2004.
- ❖ *Learning from people who have had strokes*. London: Modernisation Initiative Stroke Services. 2005.
- ❖ *Patients as teachers: good practice guidelines for assessment for social care and health care*. London: Lewisham Social Care and Health 2003.
- ❖ *Self management of long term health conditions: a handbook for people with chronic disease*. UK edition. Boulder, Colorado: Bull Publishing, 2002.
- ❖ Long term Medical Conditions Alliance (LMCA). *Supporting Expert Patients: how to develop lay led self-management programs for people with long term medical conditions*. 2001 (folder with information sheets).
- ❖ Department of Health. *A toolkit for older people's champions: a resource for non-executive directors, councillors and older people acting as older people's champions*. London: Department of Health Publications. 2004.
- ❖ Regional Municipality of Niagara. 2001. *T. Roy Adams Regional Centre for Dementia Care: Program Manual*. (Includes floor plans of centres).
- ❖ Lewisham Primary Care Trust. *Patient Participation Groups: A brief guide to developing a Patient Participation Group*.
- ❖ Gibbon, M. 2003. *A Guide to Involving public, Patients, Users and Carers in Developing Lewisham Primary Care Trust*. Lewisham Primary Care Trust

- ❖ Farrell, C. 2004. *Patient and Public Involvement in Health: The Evidence for Policy Implementation*. London: Department of Health
- ❖ Monkhouse, D. 2005. *Research Outcomes – Expert Patient Program*. Paper provided by D. Monkhouse, EPP Coordinator, Greenwich Teaching Primary Care Trust.
- ❖ Cooper, J. and Thompson, J. 2005. *Stepping Stones to Success: An implementation, training and support framework for lay led self-management programs*. National Health Service
- ❖ Knight, G. 2005. *Better conversations: a guide for relatives*. London: CONNECT
- ❖ Centre de Recherche Institut Universitaire de Gériatrie de Montréal. 2004-2005 Rapport Annuel (Annual Report).
- ❖ The Royal Liverpool and Broadgreen University Hospitals NHS Trust. 2006. *Care Pathway papers for Stroke, Dying and Pressure Sores Prevention and Management*.
- ❖ Green House® Project Workshop Papers 2005. (Includes floor plans of Traceway Green Houses®).
- ❖ Northwest Senior and Disability Services: Seniors Advisory Council papers.

## **Websites**

Expert Patients Program

<http://www.expertpatients.nhs.uk/>

Patient and Public Involvement (DoH site)

<http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/PatientAndPublicInvolvement/fs/en>

Commission for patient and public involvement

<http://www.cppih.org/>

National Institute for clinical excellence (Patient & Public Involvement Program)

<http://www.nice.org.uk/page.aspx?o=may2004content.aboutnice.whowear.patientinvolvementunit>

Royal Liverpool and Broadgreen University Hospitals NHS Trust Older People's Champion Network

<http://www.rlbuht.nhs.uk/content/default.asp?web=224&sub=402>

Green House Project

<http://thegreenhouseproject.com/>

NorthWest Seniors and Disability Services

<http://www.nwsds.org/index.html>

### **Relevant published articles and books**

Crombie IK, Irvine L, Williams B, Slane PW, McGinnis AR, Slane PW, Alder EM, McMurdo, M. 2004. Why older people do not participate in leisure time physical activity: a survey of activity levels, beliefs and deterrents. *Age and Ageing*, Volume 33: 287-292

Witham D, Gray JA, Argo I, Johnston DW, Struthers AD, McMurdo M. 2005. Does a seated exercise programme improve functional status and health status in frail older heart failure patients? A randomised controlled trial. *American Journal of Cardiology*, Volume 95(9):1120-4.

Mather, A., Rodriguez, C., Guthrie, M., McHarg, M., Reid, I. And McMurdo, M. 2002. Effects of exercise on depressive symptoms in older adults with poorly responsive depressive disorder. *The British Journal of Psychiatry*, Volume 180: 411-415

McMurdo, M. 1997. Physical activity and health in old age. *Scottish Medical Journal*. Volume 42: 154-155

McMurdo, M. Mole, P. Paterson, C. 1997. Controlled trial of weight bearing exercise in older women in relation to bone density and falls *British Medical Journal*. Feb 22: 314:569

McMurdo MET, Burnett L. 1992. A randomised controlled trial of exercise in the elderly. *Gerontology*, Volume 38:292-8

Barlow, J., Bancroft, G. and Turner, A. 2005. Volunteer, lay tutors' experiences of the Chronic Disease Self Management course: being valued and adding value. *Health Education Research*, Volume 20, 2: 128-136

Abbott, S., Meyer, J., Bentley, J. and Lanceley, A. 2006. Patient Advice and Liaison Services: strengthening the voices of individual service users in health care organisations. *Health Expectations*, Volume 9: 138-147

Briller, S., Proffitt, M., Perez, K., and Calkins, M. 2001. *Understanding the Environment through Aging Senses*. Creating Successful Dementia Care Settings Series, Volume One. Sydney: Health Professions Press.

Briller, S., Proffitt, M., Perez, K., Calkins, M. and Marsden, J. 2001. *Maximizing Cognitive and Functional Abilities*. Creating Successful Dementia Care Settings Series, Volume 2. Sydney: Health Professions Press.

Perez, K., Proffitt, M. and Calkins, M. 2001. *Minimizing Disruptive Behaviours*. Creating Successful Dementia Care Settings Series, Volume Three. Sydney: Health Professions Press.

Marsden, J., Briller, S., Calkins, M. and Proffitt, M. 2001. *Enhancing Identity and Sense of Home*. Creating Successful Dementia Care Setting, Volume Four. Sydney: Health Professionals Press

## Appendix 1 – Reconstituted Food Program Photographs



Selection of vegetables



Salad Aspic with French Vinaigrette



Selection of main entrees



Selection of desserts available