

THE HOME NETWORK: AN AUSTRALIAN NATIONAL INITIATIVE FOR HOME THERAPIES

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SUMMARY

Background: Longer, more frequent dialysis at home can improve life expectancy for patients with chronic kidney disease. Increased use of home dialysis therapies also benefits the hospital system, allowing for more efficient allocation of clinic resources. However, the Australian and New Zealand Data Registry statistics highlight the low uptake of home haemodialysis and peritoneal dialysis across Australia.

Objective: In August 2009, the Australia's HOME Network was established as a national initiative to engage and empower healthcare professionals working in the home dialysis specialty. The aim was to develop solutions to advocate for and ultimately increase the use of home therapies. This paper describes the development, achievement and future plan of the Australian HOME Network.

Achievements: Achievements to date include: a survey of HOME Network members to assess the current state of patient and healthcare professional-targeted education resources; development of two patient case studies and activities addressing how to overcome the financial burden experienced by patients on home dialysis. Future projects aim to improve patient and healthcare professional education, and advocacy for home dialysis therapies.

Conclusion: The HOME Network is supporting healthcare professionals working in the home dialysis specialty to develop solutions and tools that will help to facilitate greater utilisation of home dialysis therapies.

KEY WORDS Haemodialysis • Home dialysis • Home therapies • Peritoneal dialysis

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BIODATA

Josephine Chow is the Foundation Chair for the HOME Network. Coming from a specialty background as a renal nurse, Josephine has been a guest speaker at many national and international conferences. As well as a Master in Nephrology Nursing and a PhD, Josephine has a Master of Business Administration. She is very active in nursing research.



INTRODUCTION

The incidence of end-stage kidney disease (ESKD) and prevalence of dialysis are increasing among Australians (Australia and New Zealand Dialysis and Transplant Registry 2011; Australian Institute of Health and Welfare 2011). The rate of diagnosis of ESKD increased from 18.9 (per 100,000 population) in 2003 to 20.9 in 2007 (Australian Institute of Health and Welfare 2011), while proportions of people with ESKD requiring regular dialysis rose from 9,260 (per million populations) in 2006 to 10,590 in 2010 (Australia and New Zealand Dialysis and Transplant Registry 2011). This growth is attributed to the ageing population and rising prevalence of Type 2 diabetes, which is the leading cause of ESKD (Australian Institute of Health and Welfare 2009; Agar *et al.* 2010). Chronic kidney disease has a tremendous impact on society, the healthcare system, individuals and their family (Australian Institute of Health and Welfare 2009).

Currently, haemodialysis (HD) and peritoneal dialysis (PD) are the most common therapies available for people with ESKD in Australia. People choosing PD often carry out dialysis at home, while HD can be carried in the hospital, satellite dialysis units, or in the home. Home dialysis confers financial benefits for the health system and also clinical and social advantages for the individuals and their family (Kerr *et al.* 2008). The estimated annual cost of dialysis at home in Australia was AUD\$49,137 (Australian dollars) (approx. 40,000 Euros) compared with \$79,072 (approx. 60,000 Euros) for in-centre dialysis (Kidney Health Australia 2010). People on the home dialysis programme can enjoy enhanced opportunities for rehabilitation and a return to work, flexibility in dialysis schedules, with time and cost savings from reduced travel to dialysis centres, thus improving the individual's satisfaction and quality of life (Agar *et al.* 2010; Pipkin *et al.* 2010; Australian Institute of Health and Welfare 2011).

Despite these considerable advantages, the use of home dialysis has been diminishing worldwide (MacGregor *et al.* 2006). A gradual reduction of home dialysis (home HD and PD) has been observed in Australia, in which the rates decreased from 50% in 1990 to 39% in 2000, 32% in 2005 and 29% in 2010 (Australia and New Zealand Dialysis and Transplant Registry 2011; Kidney Health Australia 2012). Although nocturnal home HD regimens have been implemented in Australia since 2000, the rate of home HD remains unchanged (9–10%) between 2003 and 2010. The rates of PD

continue to drop (24% in 2003, 22% in 2007 and 19% in 2010) and there has been a significant alteration to preferred PD modality of automated peritoneal dialysis (APD) rather than continuous ambulatory peritoneal dialysis (CAPD) (Australia and New Zealand Dialysis and Transplant Registry 2006, 2011). The use of home dialysis therapies varies across different geographical states in Australia (Figure 1). Among people requiring dialysis, the percentages using home HD and PD in 2009 were 14% and 28% in New South Wales respectively, 10% and 20% in Queensland, 12% and 11% in Australian Capital Territory, 8% and 17% in Victoria, 3% and 21% in South Australia, 5% and 25% in Tasmania, 7% and 8% in Northern Territory and 4% and 22% in Western Australia (Kidney Health Australia 2012).

The decline of home dialysis is associated with a growth of satellite dialysis units staffed by dialysis nurses (Agar *et al.* 2010), and the increasing age and co-morbidity of the dialysis population (MacGregor *et al.* 2006). Additional reasons from the patients' perspective include fears of, and low level of motivation for home haemodialysis (HHD), lack of self-care ability and family supports, and inadequate resources available such as respite care and financial incentives (Sinclair 2008; Agar *et al.* 2010; Lauder *et al.* 2010; Ludlow *et al.* 2011). From the health professionals' perspectives, there are insufficient resources in dialysis units to provide support and education to patients, whilst a lack of culture and advocacy for home dialysis are contributing to the under-growth of home dialysis (Lauder *et al.* 2010; Ludlow *et al.* 2011). However, it has been reported that medical staff are willing to recommend home dialysis for patients if patient-specific barriers are identified and dealt with (Lauder *et al.* 2010).

THE DEVELOPMENT OF THE HOME NETWORK AS A SOLUTION

Senior renal nurses in Australia recognised the need for action to reverse the decline of home dialysis availability and discussed the potential role of a working group. The HOME Network was initially conceived as a national initiative to engage and empower healthcare professionals working in home dialysis to develop solutions to tackle the low uptake of HHD. PD was incorporated into the scope of the HOME Network subsequently. In August 2009, an inaugural workshop was held with representatives of home dialysis nursing and allied health professionals from each state and territory of Australia. The workshop focused on the identification of specific barriers to the

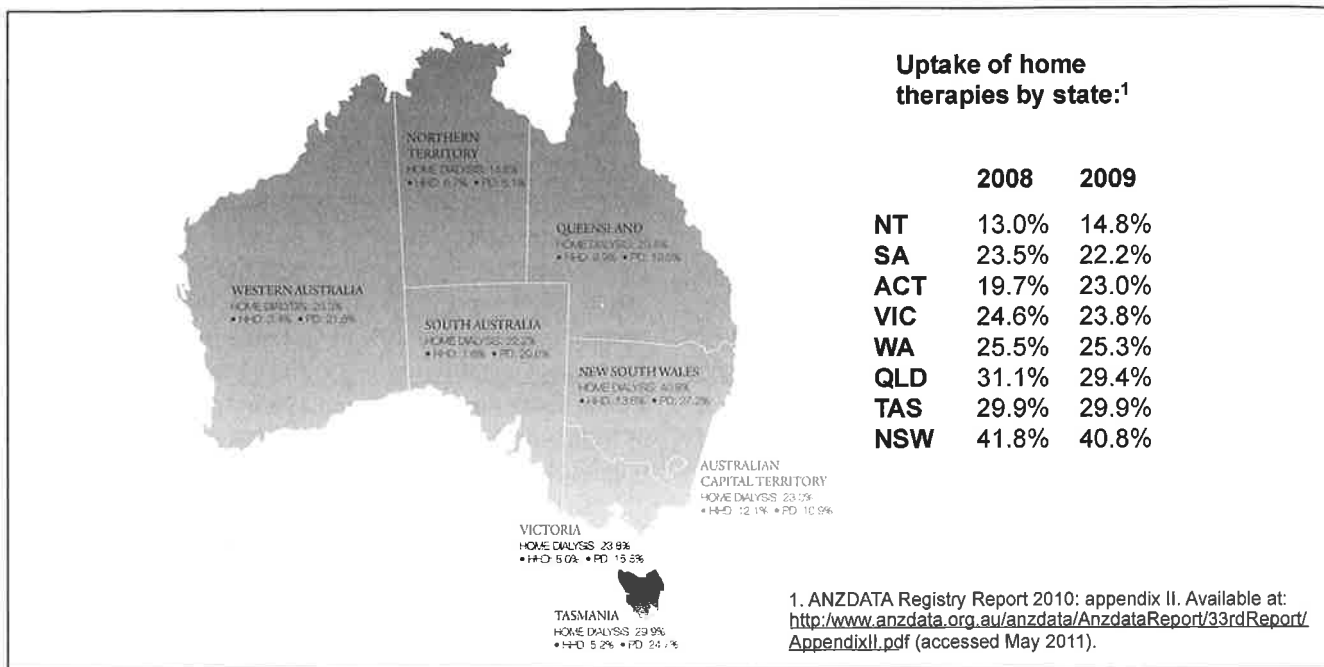


Figure 1: The use of home dialysis therapies across Australia.

uptake of home dialysis therapies. Many key factors identified include inadequate levels of knowledge and competence among dialysis nursing staff; a lack of education about home dialysis treatment options provided to patients at commencement of their regular dialysis and limited access to assessment, support and counselling services; insufficient medical advocacy for home dialysis therapies; and financial burden on the patient due to set-up and on-going costs of home dialysis therapies. Following these events, the HOME Network was officially established in February 2010. The Network mission

is 'Through education and advocacy, The HOME Network aims to enable patients and healthcare professionals to use their knowledge and the practical resources developed by the Network to empower patients to embrace the freedom of home therapies'. Initially, the Network had 20 core members representing each State and Territory. The governance framework of the HOME Network (Figure 2) includes an elected Chair, an Advisory Committee and four nominated Taskforce Coordinators. At the time of writing, there are 18 core and 19 associate members.

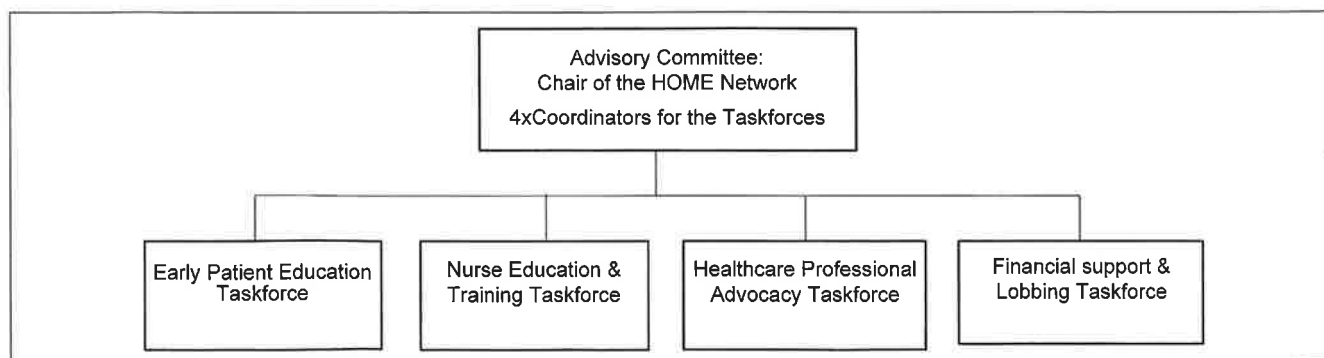


Figure 2: Governance framework for the HOME Network.

WHAT HAS BEEN ACHIEVED?

Significant steps have been taken to achieve the development of the HOME Network including bi-annual workshops among the Network members to further define the scope and direction of the Network, the role and responsibilities of the core members and partnership with other organisations including Kidney Health Australia (KHA). Four taskforces targeting the four key barriers were formed, including:

- (i) Early Patient Education to ensure the early *education* of patients on dialysis, and *empower* them with the knowledge and freedom to have dialysis at home.
- (ii) Nurse Education and Training to *enable* renal nurses with awareness and knowledge so that they may *empower* their patients to embrace the use of home therapies.
- (iii) Healthcare Professional Advocacy to *educate* physicians and other healthcare professionals about home therapies and potential benefits for patients.
- (iv) Financial Support & Lobbying taskforce which *advocate* for better financial support from Federal and State Governments, central agencies and utility provider such as water and electricity companies.

ASSESSMENT OF EDUCATIONAL RESOURCES

A survey to determine the existing educational resources related to home dialysis therapies was conducted, resulting in the development of practical resources including written and video case studies.

PRECEPTORSHIP PROGRAMME FOR NOCTURNAL HHD

The first preceptorship programme was hosted by Barwon Health in Geelong, Victoria, a unit chosen because it had successfully improved the uptake of nocturnal home HD. Discussions and experience shared in the preceptorship programme reflected the Network's key priorities including early patient education, nurse education and training, physician advocacy and financial support for home dialysis patients.

FACT SHEETS FOR PATIENTS ABOUT FINANCIAL SUPPORT

The financial taskforce in partnership with KHA created and made fact sheets available to patients, carers and healthcare providers. These fact sheets described the State and Territory specific financial support and resources available, both to inform patients and for use in the development of lobbying strategies for State government and other services providers.

Promising results are that two Local Health Districts in Sydney have provided additional resources and strong support such as introducing four senior nurse positions to work on service provision and patient advocacy and asking Sydney Water, local governments, electrical retail companies, and those tendering for home-based dialysis services to provide financial support for patients on home dialysis. Now every patient on home dialysis in both Local Health Districts is covered by a financial and services support package for their initial set up costs of dialysis in the home. Some of the patients also receive rebate for their excess electricity, water and wastage bills. In addition, funding was approved for equipment such as blood pressure machines and weighing scales. In addition, home dialysis set-up funding is also available for patients in some of the States across the country. For example, in New South Wales, all patients on Home HD can access the set-up fee. The price per treatment contract for HD consumables and equipment, which is a common procurement model in Australia, now has the plumbing costs included in the commercial agreements.

NURSING PERCEPTIONS SURVEY

The Nurse Education Taskforce of the HOME Network conducted a survey to assess nursing knowledge and perception of promoting home dialysis therapies. According to the survey respondents ($n = 116$) the main obstacles to a successful home dialysis promotion include patient difficulties such as poor socio-economics, medical issues and lack of support at home. Pre-dialysis activities such as educators visiting the units, and the involvement of home dialysis staff and patients into the units were often necessary.

OTHER INITIATIVES

There is ongoing collaboration between the HOME Network and KHA to ensure the promotion of home dialysis, which led to the creation of a new position in 2001, the National Home Dialysis Project Manager who is directly employed by KHA. The creation of the Home Dialysis Project Manager has provided the opportunity to support the HOME Network in moving forward with ownership, recognition, completion of projects and direction. Furthermore, the adoption of co-ordinators' role within Taskforces has ensured the empowerment among the Network's members. The HOME Network Advisory Committee and the Chairperson have strong commitment to drive the future and outcomes of the HOME Network, resulting in an increasing credibility of the Network.

Marketing strategies included tri-annual newsletters for the renal community, monthly updates (available for download from www.homedialysis.org.au/publications) and exhibition stands at relevant national conferences. The KHA National Home Dialysis Project Manager with support of the HOME Network members has developed an inaugural home dialysis website which went live in August 2012. The content of the home dialysis website (<http://www.homedialysi.org.au>) includes sections for consumers and health professionals, providing information about home PD and HD, patient training programmes and tools, home dialysis units and supports at home and healthy lifestyle as well as up-to-date research evidence.

THE WAY FORWARDS

The HOME Network has established itself as a respected group of professional individuals who can influence practice related to home dialysis throughout Australia. The group is now taking the next step and developing an original research project to address knowledge gaps about the patient's perception and support needs when on home dialysis. Gaps in knowledge about the costs to patients, including medications at home are being further assessed in order to inform policy. The HOME Network continues to be the major consultative partner for the development of educational materials that promote home dialysis.

Recognition, affiliation and funding are critical to the Network's long-term function and discussion is in progress in formalising partnerships with KHA, seeking endorsement from nephrological professional societies such as the Renal Society of Australasia, the Australia & New Zealand Society of Nephrology and international associations.

TRANSFERABILITY AND IMPLICATIONS FOR PRACTICE

The model of the HOME Network can be easily transferred to other professional associations, both nationally and internationally. The experience at the HOME Network presented here highlights the importance of a vision and thorough stakeholder engagement by senior clinicians who are passionate about home therapies. The following are some of the key elements for success:

(1) Selection of membership

The task force brings in people from diverse backgrounds and localities and the membership is proportionally well represented amongst the different States in Australia. The membership consists of multiprofessional experts to ensure

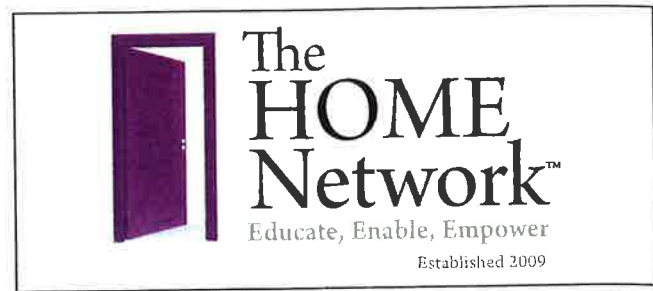


Figure 3: HOME Network's Logo.

a broad spectrum of opinions and expertise. Consultation includes a biannual workshop, teleconference, brainstorm session and survey. In order to promote interest in the initial set-up phase, a kick-off event was conducted which resulted in confirmation of an enthusiastic membership to serve on the taskforce.

(2) Establishment of the HOME Network's identity

At the HOME Network's second workshop, the members provided valuable input into the design for the HOME Network Logo (Figure 3). The open door image represents 'a door to freedom', which highlights the importance of developing solutions to address the barriers that currently prevent increased uptake of home dialysis therapies. The HOME Network can help patients achieve the freedom to dialyse at home, rather than being restricted to a routine, built around regular visits to a dialysis unit. The development of the HOME Network mission statement also reinforces the group's purpose, passion, plan and persistence.

(3) Selection of appropriate projects and identification of timelines

The group worked together and within four taskforces to further develop project plans and determine action points for follow up. Goal setting for each taskforce and projects are clearly documented, discussed and agreed on.

(4) Alignment and consultation with stakeholders

Stakeholders include nephrologists, nursing staff and allied health staff. It is important to identify potential partners that have the same vision to promote home therapies. Professional bodies such as KHA have been represented within the HOME Network since the first workshop in 2009, alongside other core members.

(5) Preparation of bi-annual workshop

It is crucial to define clear objectives and expected outcomes for each workshop with intensive planning, prior to the event. Feedback from the progress of projects within each taskforce is paramount. A briefing document of the workshop outlining the details of each activity in the programme was developed for each workshop faculty prior to the workshop. This has greatly enhanced effective use of time during the workshop.

(6) Finance and sustainability

The budget for each workshop and projects was drafted and meticulously planned to optimise the use of the available funding. The funding covered the running cost for the face-to-face workshop (flights, accommodation, catering and venue hire) and projects (e.g. development of a DVD, printing and photocopies).

(7) Leadership

A designated chairperson was confirmed at the first meeting to ensure that there is a single identified person to liaise with the governing body, professional associations and task force members. The chairperson should have good communication and organisational skills, demonstrated ability to motivate members and the ability to manage relationships among both internal and external agents.

(8) On-going evaluation

Verbal and written feedback is encouraged from the members of the HOME Network and other nephrology associations.

CONCLUSION

Home dialysis therapies have been proven to be cost-effective and patient-friendly modalities compared with in-centre therapies. However, there is a decline in the uptake of home therapies in Australia. The HOME Network has been established as a national initiative to engage and empower healthcare professionals working in home therapies to develop solutions to advocate for, and ultimately increase the use of home therapies. Although the HOME Network is still in its infancy, major milestones have been achieved. The success of the HOME Network requires knowledge, meticulous planning, capital investment and confidence and commitment of the whole renal team.

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None.

CONFLICT OF INTEREST

No conflict of interest have been declared by the authors.

AUTHOR CONTRIBUTIONS

JC: Principal Project Leader; conceived project; participated in design and co-ordination; helped to draft manuscript; read and approved the final manuscript. DF, J-AM, RS, MT: Read and approved the final manuscript.

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