

'It's like you're from another world' – the voices and priorities of Victorian rural consumers who have to travel to city hospitals

Jackie Mansourian¹

¹Health Issues Centre, Victoria

Several metropolitan hospitals' Community Advisory Committees (CAC) in Victoria expressed concerns about the range of issues faced by rural consumers when using city hospitals. Health Issues Centre (HIC) which supports the development of the CACs across Victoria listened. HIC proposed developing a discussion paper on 'The needs of Victorian rural consumers who travel to Melbourne Hospitals'.¹ The work was funded by the Statewide Quality Branch of the Victorian Department of Human Services (DHS).

The preparation of the discussion paper had key stages:

- development of a Reference Group, with equal membership of rural consumers and carers with direct experience of travelling to Melbourne for health care
- literature review bringing together diverse research and advocacy papers;
- the collection and analysis of statistical data of hospital admissions to Melbourne hospitals by rural patients which helped to identify overall pathways of referrals and destinations of rural consumers to Melbourne hospitals;
- consultations with sixteen diverse consumers and carers, mostly from the Loddon Mallee region
- contacts with key health services in the Loddon Mallee region
- analysis of data and learnings, both qualitative and quantitative data,
- development of conclusions and recommendations in discussion and collaboration with the Reference Group.

The heart of the discussion paper were the stories of sixteen different consumers and carers of trying to access health services outside their rural communities.

Key issues and priorities of action

Five key issues were consistently identified throughout the poignant stories of rural consumers and carers and strongly reinforced by the findings of the literature review.

Each issue will be presented separately, even though they are interrelated and reinforce the complexity of the experience for rural consumers and carers. Priorities for action are included under each issue. These were priorities which arose from the reflections and ideas of consumers and carers during the consultation, and were reinforced by the discussion of the Reference Group and findings from the literature review.

¹ For the complete discussion paper *The Needs of Victorian Rural Consumers Who Travel to Melbourne Hospitals* go to HIC website www.healthissuescentre.org.au

1 Lack of acknowledgement of vast distances and complexities of travel for rural consumers and carers

Rural consumers and carers consistently experienced a lack of acknowledgement of the complexities of travelling for care whether for diagnosis, treatment, rehabilitation and across various health services. Barbara, a mother of two children with cystic fibrosis who had travelled over many years to Melbourne for care, said:

...there's a great deal of talk about providing a service for you, but not [about] acknowledging that you had to get here

Laura is a remedial massage therapist in a rural area in the high country of Victoria and provides care to many older residents in her community. She is also a consumer who has had different occasions to use regional and metropolitan health services. She said that the lack of acknowledgement of distance and travel is not only relevant to city hospitals but also to regional health services. She also explained that this impedes the health service's capacity for flexibility and coordination for multiple services on the same day of travel for the consumer.

She stated:

What happens is that routinely people will have to get themselves down to Melbourne. They will find that the specialist will tell them that they have to have tests.... The tests then are not run right away, so they have to go all the way home to then travel all the way back to Melbourne to have the tests. They return home again. They have to wait to get the results of that and then go back to talk to the doctor again. If surgery is the option—as in most cases it is—they have to go back down. The doctor says “I want to see you again after surgery for 4–6 weeks”. In the meantime, if they are discharged from hospital in Melbourne and they do not have after-care things organised with (neither the treating nor the local) hospital. They're left high and dry here. [The distance that Laura is talking about is over 350 km one-way].

Margaret was the carer of her husband who had open heart surgery in 2005 and was diagnosed with motor neurone disease in early 2006. The couple are also from a small rural town 200 km from Mildura and over 390 kms from Melbourne. For the treatment and care of her husband's dual conditions, they travelled to different specialists and hospitals in Mildura, Horsham, Ballarat and Melbourne many times over.

Margaret did not define the actual travel and the distances involved as onerous. Her comment was that, “You just do it.” However, interacting with the health services adds complexity:

Just a little bit of concern and interest might be helpful. You say you're from your home town and they say “where's that?” And when you say where you are, it's like you're from another world. Some people just have no concept of that at all, and it's not their fault because they live in the city. But they just have no concept of the services that are [and are not] available.

This lack of attention underpinned many critical complications experienced during the care received. It is clear that there needs to be clear and consistent recognition of travel support as integral to the provision of health services for rural consumers.

Priorities for identifying rural consumers and carers throughout the continuum of health care

The Reference Group saw mechanisms for consistent identification of rural consumers along the whole continuum of health care as crucial.

They suggested issuing rural consumers with a Rural Card (similar to the Department of Veterans' Affairs Gold Card) as one direct means of identification. Another mechanism that can be considered

includes a 'rural flag' on patient and hospital records, or one that is more easily integrated within existing hospital procedures.

Whatever the mechanism for easy identification of rural consumers, its importance lies in readily and consistently triggering health care providers to consider and facilitate appropriate travel, accommodation, and social support needs, at both system and individual levels.

2 Inconsistent and inadequate availability and provision of information about travel support and options across all services

The consumer interviews revealed inconsistent and ad hoc provision of information and communication about travel assistance, accommodation and other support services from all levels of health services.

Richard was a man in his seventies from a small town in north-west Victoria (200 km from Mildura). After being hospitalised for a week following a heart attack emergency, Richard had to come to Melbourne for an angiogram. Nobody had asked or said anything about how he would be getting there. He and his wife shared the driving of a journey of over four hours. Richard had to be in hospital for two days in Melbourne. His wife drove to Ballarat, a further two hours from the city centre, on the same day, because she had relatives with whom she could stay. Accommodation for his wife was not discussed at any point during the process of referral and reception. In his frustration at not being asked nor given any information, he stated bluntly:

...we were on our own.... at least when they're making the appointment for us to go to Melbourne, it could be discussed as to how you're going to get there and where you're going to live while you're there.

Over and over again, many rural consumers and carers reported they simply did not know about travel assistance schemes—Victorian Patient Transport Assistance Scheme (VPTAS), community transport alternatives and/or social support services that existed locally. Five of the 16 consumers and carers were not informed about accommodation alternatives, neither at regional centres nor in Melbourne.

Susan, a nurse and not yet retired, cared for her husband with cancer. When her husband had to have surgery in Melbourne he went to a private hospital. No support was given either from her GP, or the specialist, or the private hospital in Melbourne. She stated:

It was assumed we'd find accommodation...but we were floundering and I am a nurse.

On the other hand, Natalie's story attests to positive experiences when information and support is provided well. As a mother of a young child born with a chronic illness, Natalie explained:

We have crossed the right people within those services very early on...they have passed on the right information for us to be able to coordinate everything to fall into place.

And indeed there are diverse regional initiatives which do respond to travel support information needs, although they do not appear to be coordinated, or uniformly available.

Priorities for improving quality, availability and provision of information about travel support locally

It is clear that the consistent provision of information is closely associated with effective integration of travel support in health service provision and care coordination. Priorities and actions for integrating information on travel support *as part* of effective health care provision and coordination are discussed in the next section. However, here priorities are defined about the actual quality, availability and dissemination of travel and accommodation support at a broader, community level.

Three levels of improved information provision are prioritised by the Reference Group.

First, as a minimum, there exists a need for clear communication and public information provision from the Department of Human Services about Victorian Patient Transport Assistance Scheme (VPTAS) and its various entitlements. This is compatible with Recommendation 13 from the Federal Senate inquiry into patient assisted travel schemes. VPTAS needs to be marketed more effectively locally and across all levels of health care services.

Second, the preparation of an integrated and 'whole-of-travel' information package accessible to consumers and carers. That is, bringing together all locally provided public and community transport alternatives, travel support schemes (VPTAS), and accommodation, to be publicised *as a whole*. This could allow rural consumers and carers to consider what transport and accommodation alternatives better suit their needs.

The positive initiatives which do already exist in this area need to be acknowledged more broadly and supported. For example, the Accommodation Guide developed by the Mallee Division of General Practice could serve as a model for other regions as well as be more actively utilised.

Third, a coordinated, direct, face-to-face approach of giving and sharing information on travel assistance and transport options for health care *prior* to people needing health services. The Reference Group was especially clear about the need for such a community-based approach as their experience confirmed the experience of other consumers consulted—that once people and families are affected by illness they can feel constrained and reluctant to pursue such detail.

3 Inconsistent consideration and integration of travel requirements in service provision and care coordination

Many consumers' stories revealed difficult experiences about the lack of consideration by services, whether metropolitan, regional or district. This was evident not only in the lack of communication about their travel needs and support, but also in inadequate appointment options, lack of consultation with consumers about timing of appointments and about care on their return home after treatment.

Christopher, a retired man who is also a volunteer driver with the local shire council community transport scheme, reflected on his experience:

People might have a 4.30pm appointment about two hours away, and they apologise... But there's nothing they can do about it... some of the receptionists aren't aware of distances, and quite often they'll say be here at 7 o'clock in the morning to enter into hospital. Well, surely receptionists, when you're making an appointment, should be aware of who you are or at least ask how far away you are or something like that.

Richard, who was receiving rehabilitation services after his heart attack, talked about the inappropriate timing for exercise programs, which did not take into consideration the travel time for more remote consumers to and from regional centres. He stated:

The sessions they have organised down there... don't start until 3 o'clock in the afternoon and they go for an hour and a half, so then I'm faced with a two-hour drive home.

Other consumers and carers also appeared to fall in a void between discharge from hospital and home. Robert who had been receiving treatment for cancer for over the past 16 years and was involved in health matters and committees in his local community, called it "a real weakness in the system" when consumers in metropolitan and regional hospitals, and those seeing specialists, are returning home without clarity of follow-up or rehabilitation and without being connected to more localised services.

On the other hand, Natalie's positive experience suggests direction for improved care coordination and integration of travel support along the continuum of care. She attended a specialist clinic at a Melbourne hospital to access treatment for her young daughter with a chronic condition. Staff at the clinic acknowledged the three and half hours of travel and gave appointment times accordingly. A social worker provided practical travel support information immediately and linked them to a social support group.

Other consumers noted the critical coordination roles played by key workers such as GPs, palliative care workers, social workers in regional and city hospitals, and 'case managers' in rural hospitals and community health services. They had been crucial in helping consumers to make successful transitions home and to local rehabilitation after treatment away. Thus such supportive care is clearly possible.

Consumers consistently identified the need for 'rural liaison staff' throughout their care, "*someone who actually knows the system*", someone who could inform and assist consumers and carers in the coordination of their travel, accommodation and other care issues. This, they said, needed to start right at the country GP's rooms.

After receiving metropolitan care, another consumer suggested that people be directly discharged to their local rural hospitals from which home-based care and rehabilitation could better be coordinated.

Priorities

Priorities for action care towards integration of travel support in information provision, service delivery and care coordination for consumers and carers across the continuum of health

For rural GP and specialist practices:

- A 'rural liaison' role be integrated into the role of practice nurses and managers in GPs' and specialists' practices
- Provide support to GPs as the key communicators between specialists and rural consumers

For metropolitan and regional hospitals:

- Development of policies and resources to assist staff to better integrate travel support in coordinating care and programs for rural consumers. This may mean the creation of "rural liaison" specific positions, or the better integration of the supportive roles into a wide range of existing positions.
- Establish standard procedures for flexible and efficient appointment and program times which takes into account travel of rural consumers and carers
- Stronger collaboration by metropolitan and regional hospitals with rural hospital staff and services, including training, ongoing support and communication via 'telehealth' technologies
- Increased awareness by metropolitan health services of the services available to rural and remote consumers to enable more informed and coordinated discharge planning.
- Increased support and dissemination of existing initiatives by regional health services such as the Mallee Division of General Practice's website called *Connecting Care*.

For rural and regional hospitals:

- Establish/strengthen the role of care coordinators in district/rural hospitals for rural consumers returning home after treatment away, in order to facilitate coordination of and access to primary and allied health services and social support networks.

For Department of Human Services:

- Provide resources and facilitate directly the ongoing relationships, communication and coordination between metropolitan, regional and rural health services
- Development of policy and standards which recognises travel support for rural consumers and carers as an integral part of health care provision

4 Insufficient recognition of the additional psychosocial burden of travel on rural consumers and carers

Rural consumers and carers clearly articulated the stress of illness and the additional burden of travel and isolation.

Richard said that although he couldn't complain about the way he'd been treated medically:

...the medicos, the ambulance people and all the rest, their work has been tremendous, but it's just that lack of support that we're getting outside of the actual operation.

Susan's husband had private cancer care in rural and city areas, and she explained:

As a carer I would have loved to have been able to have spoken to somebody about the non-medical side. There was no one to speak to, especially when my husband became no longer competent to make decisions.

Consumers and carers clearly identified the need for **both** professional and peer-based psycho-social support.

Natalie explained the importance of peer support through her experience in a parents' group connected to the specialist clinic her child attended:

It's a totally different support with the parents and we've gained a lot of information ... that we wouldn't have got from professionals.

The priorities of action are relevant to all health services across the continuum of care in the integration of supportive health care:

- Recognise the importance of providing ongoing resources and professional psycho-social support to both consumers and carers.
- Develop/strengthen diverse and responsive social support initiatives, with particular attention to peer support, through one-to-one mentoring and/or in groups, locally or internet-based.
- Develop and strengthen collaboration with other social and community sector organisations and initiatives.

5 Limited provision of appropriate and adequate transport support and accommodation

The financial and psycho-social burdens of travelling to the city for health care clearly remain with the consumer and family.

For example, Barbara, who has cared for her son with cystic fibrosis for over 30 years, stated that VPTAS barely covers 25% of her travel costs.

Patricia, a single mother, also felt the financial constraints were numerous during her treatment for breast cancer, exacerbated by not working during her treatment. The cost of travel and the concomitant inadequacies of VPTAS in not meeting the real costs of travel in rural areas were part of the reasons that Patricia moved from her home in a small rural town to Melbourne for breast cancer treatment.

She then had to find accommodation for herself and her young nine-year old son:

I needed to find long-term accommodation for both him and I, and that's where my problems began in terms of finding...a place that would accept the two of us as a family unit. There were multiple places available for me as an individual but (not as a family)... .. What I was forced to do was drift...I had about five different places that we drifted from, which wasn't very pleasant ... some days I was recovering from chemotherapy and I was quite sick.

Then, there were the high costs of accommodation. Barbara mentioned that the Transplant Unit at one Melbourne hospital does have arrangements with various private accommodation providers. But the costs are still high: up to \$130 per night when the VPTAS subsidy was only \$60 per night if the carer and consumer were both staying.

However, many of the positive experiences of consumers and carers in relation to accommodation did focus on those managed by their city or regional hospital, public or private. They noted that importantly such accommodation was low-cost, accessible, and allowed for both consumer and carers to informally connect and support each other.

Robert , who had been receiving treatment for cancer for the past 16 years and was involved in health matters and committees in his local community, raised concerns about how over-subscribed and under-resourced community transport services are.

He explained:

You've got community transport taking up to three or four people in the car...which means it's an all-day job instead of a part-day job. And if one of those patients is incontinent and has a problem...how unpleasant it is for the volunteer driver, the carer and the other patients. That's a common occurrence I'm told...there are different people at different levels (including people with dementia) using the same car the same time...

Community transport is organised throughout Victoria by local councils, community health services and other non-governmental community service organisations, including the Red Cross, which coordinate volunteer drivers and cars.

Margaret's poignant circumstance, living in a remote town and caring for her husband with motor neurone disease highlighted another limitation of existing transport, in this case in air ambulance for carers.

...they kept saying to us that I could be put off, that I could be left somewhere if there was an emergency and they had to pick another patient. I could be left anywhere. And my husband couldn't speak, couldn't move at all and he needed me there as full-time carer.

To address these issues, three key streams of solutions were offered by consumers and carers. These related to improving VPTAS, improving access to affordable accommodation and strengthening existing transport options, for consumers and carers.

Priorities in improving travel support provision and alternatives

Improving VPTAS:

- Increase the travel and accommodation allowances to reflect the real costs
- Streamline form-filling procedures for GPs, specialists and consumers
- Provide clear, consistent information about VPTAS entitlements
- Enhance dependent and carer eligibility

Affordable, accessible accommodation options

Some accommodation clearly exists at hospitals, but when such managed accommodation is not possible, timely information about alternatives is critical. Patricia also suggested a registry of family-style accommodation near all major urban hospitals, and a purpose-built family accommodation.

Strengthening existing transport options

- Increasing financial support to community transport
- Provide adequate support to volunteer drivers within community transport
- Provide guaranteed places to carers in air ambulance travel.

Presenter

Jackie Mansourian is a Senior Projects Officer at the Health Issues Centre.