

Amaryllis House

**A review of the service model and the added value of the
service for residents and their family/whanau**

Prepared by Alison Gray

for the

Amaryllis House Advisory Group

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Acknowledgements

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About the author

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Table of contents

Executive summary.....	3
Introduction	6
Amaryllis House philosophy of care	6
Research questions	7
Relevant literature	10
Administrative data.....	11
Staffing.....	15
Amaryllis House as a “home”	18
Support services	21
Safety and security versus independence	24
Changes in the way Amaryllis House operates.....	25
Residents and their families’ views of the service.....	26
Aspects of the service that could be improved.....	30
Comparisons with other services	33
Conclusion	36
Appendix 1 Letter of support.....	38

Executive summary

1. Amaryllis House, the residential service supporting people with Huntington's disease (HD), opened in Lower Hutt in September 2004. The service was developed by NZCare who won the contract from the Ministry of Health.
2. The service was based on two fundamental principles that apply at all stages of the disease. These are that:
 - all people irrespective of their health or disability needs have the right to live as normal a life as possible
 - all people have opportunities to maximise their independence and have control over their own life and decision making.
3. Another set of principles guided NZCare in developing support services for people with Huntington's disease. They are:
 - a range of support services need to be provided to ensure choice and decision making opportunities
 - residential care support must be designed to ensure the principles of normal living are supported
 - personal security
 - maintaining maximum autonomy and self determination.
4. This project looks at how well the service meets the need of residents and their family/whanau.
5. Information was gathered through an analysis of administrative data and tape recorded face to face interviews with:
 - a sample of the 17 staff at the facility, including all senior staff
 - two of the 12 permanent residents in the facility - the condition of others did not allow an interview
 - eight family members of residents
 - health professionals who have regular contact with the service
 - people who have family members in residential facilities at other sites.

Administrative information

6. Administrative information was provided by NZCare and Amaryllis House for the year 1 July 2006 to 1 July 2007. The information shows that clients' had far fewer behavioural issues following admission to Amaryllis House. They also made significantly less use of inpatient, outpatient and residential mental health services.
7. Four residents were admitted to hospital in the year 1 July 2006 to 30 June 2007. One was an elective admission for treatment unrelated to HD. The staff reported an average of one infection per month. These were often chest infections or skin-related. Two hundred and forty-nine accidents and incidents were reported for the 2006/2007 year. They included 107 behavioural incidents, 107 bruises and falls, 19 medical incidents and 16 other incidents, such as becoming entangled in the bed railings.

Management and staffing

8. Amaryllis House is staffed by a Manager, Care Manager, both of whom are registered nurses, an enrolled nurse and 17 support workers. A part-time recreation worker organizes outings, activities and social events for residents. Staff turnover since the House opened has been extremely low, with three resignations in 2005, three in 2006 and none to end of June 2007.
9. The management team is supported by an Advisory Committee which is able to provide independent input to assist the managers in maintaining quality care and to afford appropriate change if and when they think it is necessary. Both staff and family members agreed that strong leadership is the key to the success of the unit.
10. Family members were extremely appreciative of the benefits of a stable staff, who built up a pool of knowledge about HD. Staff know and work with all the residents and follow protocols developed to ensure that all staff members adopt the same approach, which maintains consistency. Managers were clear that, with HD residents, it is essential to have at least two staff on at all times for safety and to provide support.
11. The Manager and Care Manager have both attended a two day seminar on Positive Approaches to Behaviour change facilitated by Dr Michael Reid, who also offered a full-day training session at Amaryllis House. Staff receive ongoing training through in-house sessions and opportunities to attend study days and workshops.

Does the residential unit function as a “home” and support the principle of normal living?

12. Within the constraints posed by residents' condition, Amaryllis House functions very well as a home. Residents have as much control as they are able over their own lives. Staff have been able to maintain a homely environment, and encourage those who are able, to engage in activities and go on outings.

Does Amaryllis House offer a range of support services that provide clients with choice and decision making opportunities?

13. Amaryllis House has access to a range of support services – a GP, occupational therapist, speech language therapist, dentist, social worker and psychiatrist, if required. A podiatrist, hairdresser, and representatives of church group are also available and residents have access to dentists through the public system. Residents have relatively little choice over who provides particular services but they can choose whether or not to use them.

Is there an appropriate level of clinical expertise available?

14. Management make most of the decisions about residents' need for clinical services, usually after consultation with support workers. This is because residents are not always aware that they are having problems or they can be unwilling to accept that they need help. The managers discuss their intentions with residents if they can; otherwise they discuss the options with family members. The level of expertise available is appropriate.

Does Amaryllis House acknowledge personal security needs and allow clients to maintain their safety and dignity at all stages of the disease?

15. Residents agreed that they felt safe in Amaryllis House. Staff, families and medical specialists agreed that the nature and level of security offered inside and outside the house is appropriate and as unobtrusive as possible. Locks have had to be installed on the front and back door in response to residents' behaviours.
16. Families are asked to decide what they would like done should their family member have a life-threatening illness or require resuscitation. The staff have developed forms for family members to sign based on the regimes used in the hospice to reduce family distress. This has provided security and comfort for family members and guidance for staff.

Does Amaryllis House operate in the way it was originally planned?

17. The original plan to have 12 permanent beds and two respite beds at Amaryllis House has changed. With the demand for places, the Ministry of Health has agreed to make one of the respite care beds permanent, but the second bed is also under pressure. The condition of some of those who come for respite care has been so serious that it is not appropriate for them to return home.
18. Residents' prefer to congregate in the large communal area rather than using the smaller lounges provided in each wing. In any new facility it may be preferable to offer a single second lounge to provide a quiet space for families to meet together. All bedrooms need to have attached bathrooms.

Do residents and their families, and families using other services, think that Amaryllis House offers a high quality and appropriate service?

19. The residents and all family members interviewed were extremely positive about Amaryllis House. They liked the quality of care, the security and safety it offered, the friendliness of the staff and, in particular, the responsiveness of management. They found the "open door" policy welcoming and were grateful for an opportunity to regain some normality in their own lives.
20. The fact that family members had so few complaints was an indication of the high quality of the service offered at Amaryllis House. Any complaints they did have were addressed promptly. None were systemic or of major significance.

Do residents and families have any comments on the advantages and disadvantages of having a specialist service?

21. People who had or had had family members in other services could clearly see the benefits of having a dedicated service. They described situations in other services where the physical care was poor; where staff tried to make residents fit in with the institution's routine and where they simply did not understand about HD.

Introduction

Amaryllis House, the residential service supporting people with Huntington's disease (HD), opened in Lower Hutt in September 2004. The service was the first of its kind in the country and reflects the commitment of the families and the Huntington's disease Association over a period of about 30 years to get a dedicated facility. For many years the families had been frustrated by not having access to specialised services. Often family members ended up in inappropriate placements in psychiatric hospitals and aged care facilities. Families also felt uncomfortable about seeing a family member displaying extreme behaviours in residential services that were not used to dealing with this issue.

In 2001 the Ministry of Health conducted a tender process in the Greater Wellington area to find a provider to develop the residential service. NZCare was the successful provider. A temporary residential service was established in a rented house in 2002 before the new premises opened.

The service is not based on replicating an established model of service provision; it is a unique service guided by the best practice, experience and wisdom of the families and professionals involved.

This project looks at how well the service meets the need of residents and their family/whanau. The information will be used to inform further service development initiatives. It will also be valuable to clients, their families, and to funders such as the Ministry of Health, and to the needs assessment service coordination agencies.

Amaryllis House philosophy of care

The service was based on two fundamental principles that must apply at all stages of the disease. These are that:

- all people irrespective of their health or disability needs have the right to live as normal a life as possible
- all people have opportunities to maximise their independence and have control over their own life and decision making.

Another set of principles guided NZCare in developing support services for people with Huntington's disease. They are:

A range of support services need to be provided to ensure choice and decision making opportunities. Services should include

- home support to ensure people can remain at home for as long as possible if this is their wish
- independent living support to ensure people can live independently for as long as possible if this is their wish
- respite care support to ensure people can remain at home or in other community living arrangements for as long as possible
- day care support to provide a wider range of activity for people and to ensure people can remain in their community living arrangements for as long as possible
- residential care support in a community based environment designed to meet the changing needs of the person for life time care.

It is not considered sufficient to provide residential care services in isolation. These must be part of a total concept of care which supports the philosophy of care summarised above.

Residential care support must be designed to ensure the principles of normal living are supported. This means providing at least the following:

- a home like environment
- private personal space
- privacy and the maintenance of dignity for all personal cares
- opportunity and support to maintain all aspects of personal care and living for as long as possible
- choice in activities and living spaces within and around the home
- the opportunity and facilities to entertain family and friends in the home
- flexible facilities to meet the changing needs of people as dependency increases and treatment methods evolve.

Note: The residential unit must function as a home. This means the function of staff is to assist people to live in their own home. Staff will assist with personal cares, outings, washing of personal clothing, cooking, cleaning etc and residents will assist as and when they can.

Personal security

From time to time at stages of the disease people may require a security system to maintain their safety and dignity. The day to day staff support of residents and the design of the facility will minimise the use of secure facilities and secure care. In this way the rights of individuals will be maximised.

- Staff training will be targeted towards behavioural management and observation rather than confinement.
- Electronic monitoring will be investigated to ensure any system designed to maintain the safety of people through a secure system of entry or exit is as unobtrusive as possible.

Maintaining maximum autonomy and self determination

Residents and their families and advocates must have the ability to exercise maximum control over the day to day living of people in the residential home. This will be achieved through regular resident meetings and a formal Advisory Committee. The committee will meet regularly to advise, support and monitor the service. Residents, families and advocates will be represented on this committee.

Research questions

The research sought to answer the following research questions:

1. Does the residential unit function as a “home”?
2. Does Amaryllis House support the principle of “normal living”?
3. Does Amaryllis House offer a range of support services that provide clients with choice and decision making opportunities?
4. Does Amaryllis House acknowledge personal security needs and allow clients to maintain their safety and dignity at all stages of the disease?

5. Is there an appropriate level of clinical expertise available?
6. Does Amaryllis House operate in the way it was originally planned?
7. Do residents and their families think that Amaryllis House offers a high quality and appropriate service? Do they see it as a centre of excellence?
8. Are there any aspects of the service that could be improved?
9. Do people with Huntington's disease in other residential facilities and their families see these facilities offering as high a quality and appropriate service as Amaryllis House?
10. Do they have any comments on the advantages and disadvantages of having a specialist service?

Method

Because Amaryllis House is unique, this report is essentially a case study. The House is a small facility, so the range of data is correspondingly small and quite diverse given the nature of HD and its different manifestations. Residents and their family members have different needs and different expectations, and come with different experiences of other services. While the main focus in this report is on the service provided by Amaryllis House, families have inevitably made comparisons with the services they used before their family member moved to Amaryllis House. These form an important part of this report, as do comments made by those who are not able to use Amaryllis House because they live outside the area.

Information was gathered through an analysis of administrative data and interviews. Advisory Committee members made initial contact with residents and families to discuss the research and obtain their agreement to be contacted by the researcher. All participants were provided with information about the research, giving details of who it is for, what information would be collected, how it will be used and who would be doing the interviews and report writing. They were advised of their right to decline to take part, not to answer any questions they did not want to answer and to opt out of interviews at any time. All gave informed consent to an interview.

The administrative data included information on staffing and staff turnover, hospital admissions for residents, use of mental health services, as well as incidents and accidents, infections, and restraint use.

Qualitative information was gathered through tape recorded face to face interviews with:

- a sample of the 17 staff at the facility, including all senior staff
- two of the 12 permanent residents in the facility - the condition of others did not allow an interview
- eight family members of residents
- two health professionals who have regular contact with the service, a general practitioner and an occupational therapist
- two people who have family members in residential facilities at other sites.

Interviews were originally planned with clients and family members supported by Amaryllis House in the community. Only one client is in this situation and that person was not well enough to interview and no family members were available.

Amaryllis House has no residents in respite care at present.

Tape recordings were transcribed and participants were asked to agree to anonymous quotes being used in the report. These are presented in shaded boxes in the report. As far as possible, identifying information has been changed or excluded.

Because of the case study nature of this report and the very small sample, the quotes provide important information on how individuals, families and staff experience the service. They are integral to the story, rather than being simply illustrative additions to add interest.

Relevant literature

Very little research literature examines the benefits of specialist residential care services for people with advanced Huntington's disease. Nor are there many examples of services like Amaryllis House with which to make comparisons.

In Britain, a number of residential and nursing homes have small units offering specialist care for people with Huntington's disease. One, Frank Gardham House, has a similar philosophy of care to Amaryllis House, in that residents and families are encouraged to make decisions about the care provided at every stage. The management team is made up of four senior managers and four carers, who concern themselves with issues such as finance, contracts with health authorities, business planning and quality audits. Staff receive ongoing training and residents are encouraged to be as involved in the domestic life of the home as possible. Homes typically have access to a consultant psychologist, psychiatrist, dietician, physiotherapist, speech and language therapists and occupational therapists. In 1998, the 12-bedded service won the special 50th NHS anniversary Golden Helix Award for Patient Partnership.

In Australia, the Sydney-West Area Health Service has an inpatient medium term chronic care unit of 15 beds at Lottie Stewart Hospital. The unit has access to neurology/psychiatry and GP as well as social work and allied health services. Unlike Amaryllis House, patients need to be relocated as the disease progresses.

In the United States, the General Assembly of Pennsylvania has recognized the cost of caring for people with Huntington's disease. It notes that:

“The limited options for residential care are compounded by several interrelated factors:

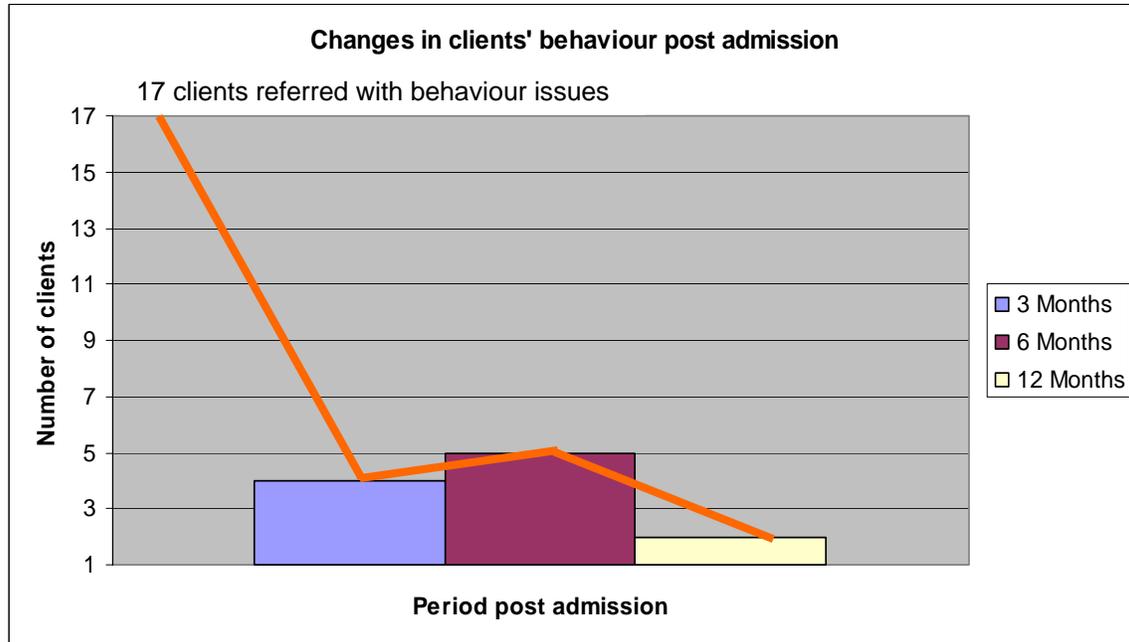
- Huntington's disease patients tend to age in place. Their long lengths of stay reduce placement opportunities for other affected individuals.
- Due to the progressive course of their disease, the care needs of Huntington's patients become more complex and costly.
- Due to the complex and intensive medical, nursing, rehabilitative and psychological care needs of this population, Huntington's disease is best treated in discrete units by an interdisciplinary team as opposed to scattered beds, a costly option for most nursing homes.
- Their care needs are more expensive as compared to the traditional geriatric nursing home resident.” (The General Assembly of Pennsylvania House Bill No. 2640 Session of 2004)/

Administrative data

The information in this section was provided by the NZCare Group and staff at Amaryllis House. Table 1 below shows that while 17 clients were identified as having behaviour issues on referral, in almost every case, those issues disappeared after admission. At three months post admission, only four out of the 17 clients had incidents involving behaviour. At 12 months, only 2 of the 14 clients that were had been resident in Amaryllis House for a year did so.

Table 1 Behaviour issues on referral and post admission

Client	Referral to Amaryllis House indicating behaviour issues	Incidents involving behaviour recorded at 3 months post admission	Incidents involving behaviour recorded at 6 months post admission	No. of incidents involving behaviour at 12 months
A	✓	✓	transferred	
B	✓	✓	✓	✓
C	✓	✓	✓	
D	✓		✓	
E	✓			
F	✓			✓
G	✓			
H	✓		✓	Not there 12 months
I	✓			
J	✓	✓	✓	
K	✓			
L	✓			
M	✓		deceased	
N	✓			
O	✓			
P	✓		transferred	
Q	✓			



Incidents

Accident and incident reports for the period 1 July 2006 to 30 June 2007 indicate that falls and bruises and behaviour incidents were most common at Amaryllis House, with an average of nine behaviour incidents and nine falls or bruises each month – see Table 2 below. In any given month, clients often had more than one behaviour incident or fall.

Occasionally falls were also associated with a skin tear, but the latter are not recorded separately in the table below. From the beginning of 2007, incidents where residents became entangled in their bed railings were recorded separately. The medical incidents are skin tears.

Table 2 Accident and incident reports

	Behaviour	Falls & bruises	Medical	Other	Total
July	20	4	-	-	24
August	9	9	1	-	19
September	11	11	2	-	24
October	9	13	1	-	23
November	7	6		1*	14
December	9	9	2	-	20
January	-	9	1	3#	13
February	2	12	3	3#	20
March	8	15	3	2	28
April	9	9	2	3	23
May	12	5	2	2	21
June	11	5	2	2	20
Total	107	107	19	16	249

* self-inflicted accidental injury # resident caught in bed railings

All incidents are reviewed to see whether any changes need to be made in managing residents. Outcomes are recorded. It is difficult to assess what the figures mean in terms of the level of incidents because no comparable figures are available from other institutions. They do indicate a willingness to identify and address issues as they arise.

Infections

The staff reported an average of one infection per month. These were often chest infections or skin-related.

Hospital admissions

There were four admissions to hospital in the year 1 July 2006 to 30 June 2007. One was an elective admission for treatment unrelated to HD.

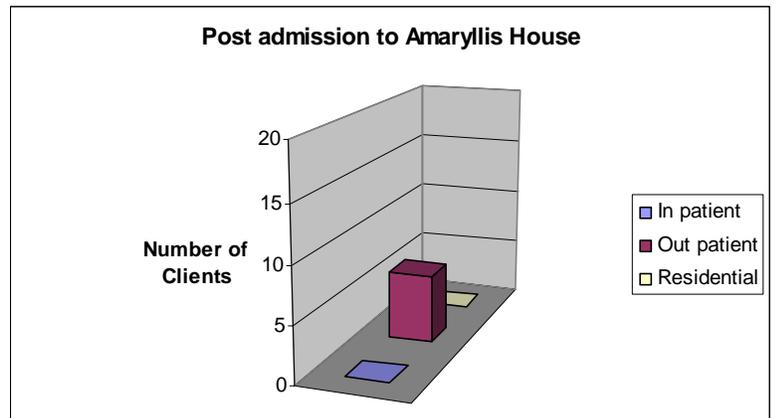
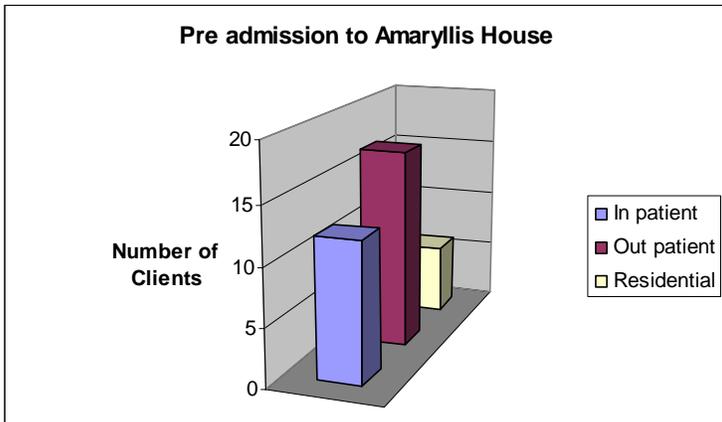
As Table 3 below shows, no clients have made use of mental health inpatient services since arriving at Amaryllis House, although 12 had done so before referral. Of the 17 who had used mental health outpatient services before admission, only five continued to do so once they were living at Amaryllis House, with one resident using an outpatient service for the first time.

Four clients had used inpatient, outpatient and residential mental health services before they moved to Amaryllis House. None had used any such services since they arrived.

Table 3 Clients' involvement with mental health services

Client	In patient services pre Amaryllis House	Out patient services pre Amaryllis House	Residential mental health services	Mental health out patient services since admission
A				
B	✓	✓		
C	✓	✓		
D		✓		✓
E		✓		
F	✓	✓		✓
G				
H		✓		
I				✓
J	✓	✓		✓
K	✓	✓	✓	
L	✓	✓	✓	
M	✓	✓	✓	
N	✓	✓	✓	
O		✓		
P	✓	✓		✓
Q	✓	✓		
R		✓		
S	✓	✓		
T				
U	✓	✓		✓

Clients' involvement with mental health services



Staffing

Amaryllis House is staffed by a Manager, Care Manager, both of whom are registered nurses, an enrolled nurse and 17 support workers. A part-time recreation worker organizes outings, activities and social events for residents. Staff turnover since the House opened has been extremely low, with three resignations in 2005 and three in 2006 and none to end of June 2007. Those who have left have done so to go overseas, have a baby, or to train as a nurse. In one or two cases, support workers have tried the work and decided it is not for them. A number of support workers worked in the temporary house before moving to Amaryllis House and have stayed ever since. Family members commented favourably on the stability of the staff and the opportunity they had to become familiar with HD.

Leadership

Both staff and family members agreed that strong leadership is the key to the success of the unit. Without exception, family members were positive about the leadership qualities of the management team.

Family member

It all comes from the top. It's an old trite saying but it's nevertheless true. They have a good team at Amaryllis, very good.

The managers themselves recognised the need to have support and an opportunity to discuss issues safely and in confidence with a colleague.

Manager

We are very lucky here. We've got each other. Other physical disability units haven't got care managers. We worked together in what was the original hospital on this site. X and I worked there for many years as Care Manager and Manager respectively. When this position came up I wondered whether I would apply. [The Care Manager] showed an interest in joining me which helped us both make the decision to apply. We both knew it would be a challenge setting up the service successfully and it helped knowing we had each others support. I rang her last night, for example, concerned about a resident and we were able to resolve the issue between us. As the only two RNs in the service this support is very important.

Advisory group

The management team is supported by an Advisory Committee which is able to provide independent input to assist the managers in maintaining quality care and to afford appropriate change if and when they think it is necessary.

Adequate staffing

Managers were also clear that, with HD residents, it is essential to have at least two staff on at all times for safety and to provide support.

Manager

The service has to be big enough to have two staff on at all times, including the night, because it's too hard to be on your own coping with a crisis or a difficulty - two awake staff all the time on site.

A stable staff

Family members were extremely appreciative of the benefits of a stable staff, who built up a pool of knowledge about HD.

Family member

The ones that are there now are the ones that were there before [in the temporary house]. They've got one girl who comes in her own time just because she enjoys it so much. Definitely who is running the place matters. And I think they have ongoing training and they support each other because they must feel it as well. Because the residents can attack you and say, "So and so's hurting me", or "So and so's doing this". You've just got to realise that's the disease and not a personal thing. They need support too. And they do understand. I can go into X and say something and she knows exactly where I'm coming from. It's specialised.

Because the house in effect, operates as a single unit, all the staff know all the residents. This helps in providing a "normal" service because residents and staff are comfortable working with each other. Staff also follow protocols developed to ensure that all staff members adopt the same approach, which maintains consistency.

Staff member

We make sure that everybody moves around. It's not a facility where you can only look after the people in that wing or say, "No, I can't go and work there because I don't know them". Everybody knows how to look after everybody here. And we have our own staff - we don't have any agency staff or anything like that, so everyone's aware of everyone's needs.

Staff training

The Manager and Care Manager have both attended a two day seminar on Positive Approaches to Behaviour change facilitated by Dr Michael Reid. He then spent a day at Amaryllis House when all staff were able to attend a full day training session. Behaviour management at Amaryllis House is strongly based on the principles taught by Dr Reid.

Staff receive ongoing training through in-house sessions and opportunities to attend study days and workshops. Staff were satisfied with the opportunities they had. Over and over again, staff and family members highlighted the unique nature of HD, with its wide range of symptoms and its different forms of expression, particularly in behaviour. They stressed the need for staff to be able to build a body of experience and learn new ways of responding.

Manager

We have stable mature staff who have had much training in understanding HD. The key to supporting people with HD is in ensuring that staff understand the disease process and how it affects the person. This means that needs are met which can be quite different to the needs of people staff previously supported e.g. the elderly. The staff make a valuable contribution to the care and lifestyle of the residents.

Staff comment

We get good training. As an enrolled nurse, there's a study day coming up. The company pays for that and [the Manager] is very good at letting people off for workshops and study and whatever else you want to do.

Family members also recognised that staff have had to learn new skills because most were unfamiliar with HD. They cited examples of situations where practice had improved or changed. Some of these are discussed in the following section. The quotes below give an indication of the changes that families have observed.

Family member

Of course it was a learning curve for the staff pretty well right from the start, HD being different but I think they've adjusted and adapted singularly well. I think possibly the manager had to speak to one of the staff about being perhaps too sharp or too familiar with one of the residents. I suppose it's easy sometimes to forget.

Family member

I'm sure the girls that work here understand a lot more now than when they first started. Initially there were some worries about there being enough staff around at times but they've improved as time goes on. They're a lot more aware and they understand a lot more.

Amaryllis House as a “home”

All those interviewed for this project agreed that within the constraints posed by residents' condition, Amaryllis House functions very well as a home.

Residents liked having their own space, and being able to have their own television, sound systems and belongings around them. They appreciated having a space to go to with their family members and being able to retreat to their rooms when the noise of the big communal room became too much. The staff also believed that given the constraints residents face because of their condition, the house works as well as it can as a home. Support workers were united in the view that it is up to them to work with residents rather than being “in charge” of them.

It's their home, not ours. We work here and we only work, but it's their home and that's what we try and class it as. [Support worker]

Visiting medical staff were just as positive, with the GP commenting that Amaryllis House is beyond compare when considering the conditions available to other patients with neurological conditions that he sees in rest homes.

Supporting the principle of “normal living”

The condition of many of the residents makes it difficult for them to engage in “normal living” but they do have as much control as they are able over their own lives. For example, if they want to sleep in till ten o'clock they can do so and they go to bed when they choose. If they want to get up at one o'clock in the morning for a cup of coffee and a snack they can. Most residents need some help in making hot drinks but all are able to get drinks and food when they want them. One resident did say he would prefer to feed himself, but staff insisted on feeding him.

Family member

He was in XX before. The staff were absolutely wonderful but it didn't work for him in the end because they were trying to make him conform to what normal people do. Like you go to bed at night and you go to sleep. At that stage he was up down, up down, up down, and they really just had to leave him where he wanted to be. Then he went to [private hospital] where they let him lie on the floor. When he got here, for a while he just slept in a chair but the next thing they had him in bed and he seems to stay there most of the night now, which is great.

Family member

He likes that there are always people round to talk to. He got pretty lonely at home, and then he started to lose confidence with going out and things like that. He likes the company and they take him out. I think a lot of their days revolve around that room, the big area there, and the tele, but they've still got their room and the other little lounges they can go to for a bit of quiet. He's got back to where he was before he went in – amazing really.

One family member was startled to find that normality extended to residents being able to have breakfast in bed.

Family member

Once when I was there, one of the residents said to [the Manager], "Do you mind if I have breakfast in bed sometimes?" And she said, "No. of course not. Why?" He said, "Well, sometimes I really just don't feel like getting up." She said, "Of course you can have breakfast in bed, and if you want bacon and eggs, you can." I said, "Hang on a minute. I thought this was Amaryllis House, not the Hilton!" [The Manager] said, "Oh no, that's no trouble." To me, that epitomised the attitude there. There's always a good attitude there."

Staff were concerned at the outset that, because of their movements, residents would be destructive and the environment would suffer, but this has happened to a much lesser extent than they anticipated. Instead staff have been able to maintain a homely environment, with plants, DVDs, stereos and television in the bedrooms, pictures on the walls and lounges available for residents and family to use.

Staff encourage those who are able to engage in activities and go on outings including swimming, going to the movies or shopping, visiting places like Parliament and having picnics. Residents particularly enjoyed these, saying they made the house feel much less like an institution. Residents also have a "happy hour" once a month and karaoke with staff and family members and they enjoyed this as well. Residents are also able to go out with friends and family members as they would at home.

Family member

He's still relatively independent. He still showers himself most of the time, dresses himself. Every now and then he has a bit of help with feeding, but he pretty much does it himself and they encourage that. They sit with him and do crosswords and so on just to keep his brain stimulated. But eventually they get past that.

Family member

I think it does function as a home for him – that's where it's warm and it's where his clothes are but I think part of him is still resentful that he's not at home. He's got a walker and he likes going out in the van. He loves that. I tell him he couldn't do that if he was at home. It's very homely and the meals are great but it's still an institution.

Although the house is designed with three wings, each with its own lounge, the residents prefer to use the large central lounge as their main area for socialising and recreation. They enjoy the company, the smell of food cooking, the kitchen and the general busyness.

The managers acknowledge that it took some time to develop a culture where carers saw themselves as guests in the residents' home rather than as being in charge. This was not surprising given that most of the staff came from services that were more task-oriented and the move to Amaryllis House has required a change in perception. They believe that having the "right" staff has been the key to making the shift successfully. The staff are mostly middle-aged, most have children, all have had considerable life experience.

Manager

Some staff find it difficult to just sit down quietly with a resident and spend time with them, talk to them. They're hard working people. It was very hard to completely knock out that whole "hospital" task-orientated routine and think of the person first. This has improved over time.

The quotes that follow are examples of the responsiveness of managers and their willingness to address concerns raised by residents, particularly in relation to ensuring that the house operates as a home for residents.

Family member

[The Manager] is very responsive. I take my hat off to her. Anything I ask for, she's great, she does it straightaway. I had an incident when one night he went out and sat on the couch. He must have put his leg up and was watching TV out in the main room. The nurse said to me, "I told him he shouldn't be out there at 11 o'clock at night and shouldn't be lying round on the couch because other people have to sit on it." She said, "I really had to growl at him and tell him he wasn't to do that." I thought, "Oh God, this is dreadful, poor man". I did tell [the Manager] and she said, "This is their home. I'll speak to her". So that was dealt with quite well. But there haven't been many things and if I do mention anything, it is done.

Managing finances and buying clothes for residents can be difficult, especially when family members live some distance away, are busy with work, or, in the case of some men, find it difficult to choose appropriate clothes for a woman whose needs are changing rapidly. They appreciated the arrangements staff made.

Family member

I've always left it to them to provide what they can - if she needs any clothes and things. It's easier for them because she's a lot lighter now than she was. The sizes have changed so I couldn't buy anything anyway. I opened up an account for them and gave them my little card so if they need any money they just draw it out of that account. They give me a record of when they draw money out which I can see anyway because I get the bank statements. But they also keep a record of where all the cash goes, what they spend. So if they draw out fifty or one hundred dollars they tell me they've used it to buy slippers or a nightie or whatever.

Support services

Amaryllis House has access to a range of support services – a GP, occupational therapist, speech language therapist, dentist, social worker and psychiatrist, if required. A podiatrist, hairdresser, and representatives of church group are also available and residents have access to dentists through the public system. The only suggestions were for occasional visits from a dietician and easier access to support services for residents with behavioural difficulties.

Residents have relatively little choice over who provides particular services but they can choose whether or not to use them. For example, they can choose whether or not to go to swimming or to use a hairdresser, or attend a church service. Those interviewed appreciated the services available including the speech therapist who helped with difficulties with swallowing, and the availability of the doctor.

An occupational therapist works with residents, staff and family members to arrange for appropriate equipment and deal with pressure care for residents. This includes specialist beds, shower/chair commodes and non-standard wheelchairs. Most decisions are made after meetings with the residents and their families. While it can be a challenge finding the right equipment, medical staff agree that the equipment is generally better than the residents would have in a rest home. For one family, this has been a boon.

Family member

We've had problems over the last few months where she's been hopping out of bed in the middle of the night, wanting to go and see somebody and crashing onto the floor. So they've been moving her out into the rec. room to try and keep a closer eye on her but about two weeks ago she crashed out of her bed and hurt her head again. So immediately that day, [the Manager] got hold of somebody and she's now got this new bed that lowers right down to the floor. A push-button thing that raises it up so you can make the bed at one level then lowers the whole thing down to the floor so she's right down there.

Staff were also satisfied with the range of services available although one person thought it could be helpful to have a dietician come in from time to time to review the food.

Staff

I do think the psych team could actually be a bit more helpful with some of our clients that we do have great difficulty with. If they could come through it would be great. I think they're a bit short on the ground themselves. We're an individual unit, we're not attached to the hospital or anything like that and by the time you get them the issue's probably over and done with. We'll have resolved it ourselves one way or another.

Clinical expertise

Management make most of the decisions about residents' need for clinical services, usually after consultation with support workers. This is because residents are not always aware that they are having problems, for example, with swallowing or they can be unwilling to accept that they need help. Staff find that getting an outside professional in can be helpful. The managers discuss their intentions with residents if they can; otherwise they discuss the options with family members.

Staff member

If we've got a problem with a resident you can usually suss something out between a group of you and you can talk to [the Manager] and [Care Manager] about it and if they think somebody else needs to be brought in, they will do that. We've got communication - we're a team and we try to solve problems if we can but if it's out of our league that's when management comes in. Sometimes too it's a doctor to change a medication or something like that.

One family member reflected on whether it might be useful to call in another specialist.

Family member

[I've heard of] a neurologist who is also a nutritionist and this person is convinced that a change in nutrition plays a huge role in the wellbeing even in palliative care. I just want to be open minded. I want to meet this person and I want to chat with him. I'm quite a stick in the mud in some ways but this time I need to be open and have a look at what we can do better for [our family member].

The doctor deals mainly with HD-related conditions such as chest infections, but a large part of his work has to do with managing the behavioural and psychiatric effects although this happens relatively rarely. A number of residents are on specialist-only medications which require the approval of a psychiatrist.

Dr Greg Young is a Consultant Psychiatrist with the Hutt Valley District Board who has seen patients with Huntington's disease referred in from other community facilities both during admissions on the psychiatric ward and when the occasion required, admissions into the general hospital. In a letter to the Director General of Health (attached as Appendix 1) he writes:

I have been extremely impressed by the care of patients at Amaryllis House. I have no doubt that the specialised interest that staff at Amaryllis House are taking patients with Huntington's disease is of great benefit to those patients and their families.

Amaryllis House also has a good relationship with the Dietary Department and the Speech Language Therapist at the Hutt Valley DHB. As soon as an indication of need arises, a referral from the GP is sent as soon as possible. Sometimes there is a delay, as there is for others in the community. The information gathered from these professionals over the last three years enables the staff to keep the residents well nourished.

Managing hospital visits

From time to time, residents are admitted to hospital. This often occurs in the weekend or overnight when the usual doctor is not available. This can cause distress because hospital staff do not always know how to deal with residents' behaviour. This sometimes means that staff from the house have to go to the hospital to help look after residents. Staff understandably prefer to keep residents at home as long as possible.

Two family members described their experiences and the importance of having someone who understands the condition. The contribution of Amaryllis House made a significant difference.

Family member

She had a spell in hospital last year. She got a virus and it really dehydrated her very badly so she ended up in hospital. Then when she got into hospital there were two girls in the ward there who used to work [at Amaryllis House] so they took over her care because she had to have someone sitting with her all the time, they took over basically. And the girls from here went to visit her, it was really good.

Family member

They don't understand the illness. It's not like MS and those others where it's a physical thing. When he was in the medical ward we had major problems. He had to have a permanent minder because he got aggressive. It was hideous really. I told them you can tell him to stay in bed but he's impulsive. They agreed to him having a minder. He couldn't feed himself but he's better now.

Managing death

Since the house opened, three residents have died. Each family wanted their family member to die in the house and that was arranged, sometimes after considerable effort. Since then the staff have developed forms for family members to sign based on the regimes used in the hospice to reduce family distress. Families need to decide what they would like done should their family member have a life-threatening illness or require resuscitation. This has provided security and comfort for family members and guidance for staff.

Staff and family members strongly agreed with the original decision to allow residents to stay at Amaryllis House until their death. The manager expressed the views shared by all those interviewed.

Manager

I know that when we were right at the early stages of designing this place there was talk about the possibility of the three wings being for people at different stages of the disease but we said no. We didn't want this, as we felt it was inappropriate to expect a person to move from what is essentially their room to another part of the building just because their disease had progressed. To do this at any stage would be very unsettling and frightening for both residents and their family.

Safety and security versus independence

Residents made few comments on security but agreed that they felt safe in Amaryllis House. Staff, families and medical specialists agreed that the nature and level of security offered inside and outside the house is appropriate and as unobtrusive as possible.

Security needs to operate at two levels – inside and outside the house. Inside, residents need to be safe in their beds, and in moving round the house. Outside they need to be safe from risks in the street and from becoming disoriented or lost away from the house.

Inside

Inside, the focus is on providing enablers rather than restraints. Some residents choose to have bed rails to prevent falls and to feel safe and secure. Where staff consider that they need cot rails, they will discuss the option with the resident or their family, if residents are unable to communicate easily. Residents also have security belts for wheelchairs, especially when they are going out, and wheelchairs adapted to their needs.

Safety is enhanced by having wide corridors to facilitate manoeuvring and good shower access.

Outside

When the building was designed, staff and the design committee hoped to be able to manage without locked doors but this had to change. The door now has an electronic code pad, and the code is changed as and when required. A gate at the back of the house has also been locked and the windows have been adapted so that they cannot be opened wide.

The building is near a number of busy roads and a railway station. The risks when residents go out are great. Some have either wandered away or actively sought to leave and been returned. They are all in the house because they became unsafe in their own homes and needed a higher level of care. Staff and family members agree that the current level of security is both necessary and appropriate.

Family member

They had to change the key pad and then he got out. But they can't go and put locks on every single window, that's a hard one. Hopefully he's got over it. It's not so much that he wanted out, but it was two or three in the morning and he wanted to go and see his brother. Another time he thought he'd go and see me at work. He didn't really think of the consequences. They were more like impulsive decisions.

Changes in the way Amaryllis House operates

Changes to the way in which Amaryllis House operates have mainly been minor and have developed from the way in which residents have used the facility.

One more significant change has been in the use of Amaryllis House for respite care. It has not been possible to adhere to the original plan to have 12 permanent beds and two respite beds. With the demand for places, the Ministry of Health has since agreed to make one of the respite care beds permanent, but the second bed is also under pressure. This is because the condition of some of those who come for respite care has been so serious that it is not appropriate for them to return home. That is the situation at present, with the remaining bed being used by a resident who is now too unwell to go home.

In some ways, the house does not work well as a respite care facility. Where people can be cared for at home with breaks, they and their families can feel distressed or at the least uncomfortable about being in a house with a group of people at an advanced stage of HD. Some decision will need to be made about how to manage respite care in the future.

Another unexpected outcome has been residents' preference for congregating in the large communal area rather than using the smaller lounges provided in each wing. This does not mean that residents, family members or staff would like to see the lounges disappear altogether, but it may be possible to combine them into a second lounge to provide a quiet space for families to meet together. They probably do not need the kitchen facilities provided, because residents are generally not well enough to make hot drinks safely.

A third change has been the need to install locks on the front and back door. This is in response to residents' behaviours. At the outset, staff did not anticipate that residents would wander or want to go out as much as they have, but as noted above, staff and family members approve of the change.

Residents and their families' views of the service

The residents and all family members interviewed were extremely positive about Amaryllis House. They liked the quality of care, the security and safety it offered, the friendliness of the staff and, in particular, the responsiveness of management. They found the "open door" policy welcoming and were grateful for an opportunity to regain some normality in their own lives.

Family members

The comments of families illustrate their appreciation of the services Amaryllis House is able to offer and the reassurance they feel from having their family member looked after by people who understand their condition. They experience a mixture of relief, guilt, security, comfort and an unfamiliar sense of returning to normality.

Relief

Family member

I just say all the time, we're so lucky we have that in Wellington. If we lived in Auckland, where would he have been? At least here they know about the food, they're focused on occupational therapy, and just what's wrong with him. I am just so thankful they built Amaryllis House in Wellington.

Guilt

The quality of care provided at Amaryllis House goes a long way to assuage the guilt and distress families feel when they can no longer care for their family member at home with or without respite care, or when they can no longer tolerate the quality of care their family member is receiving in another institution.

Family member

Having any facility is really important. This is great. It's not until you put your person into care – it's really hard to do, you feel guilty and all the rest – but you realise how incredibly different your life was. How un-normal. You thought you had a life but you realise you didn't. It eases your guilt a little bit more.

Family member

I suppose I feel guilty in a way - all the guilt and should I be looking after him as his wife? But I know I couldn't. I know that I could not deal with him at home. And resentment - I feel other women of my age go out to dinner with their husbands, they go to Elton John concerts, they go for trips to Melbourne for the weekend and I think, I'm 52 and I'm widowed but I'm not widowed.

Security

Family member

For me security is one of the big things. I know where she is, I know she's being well looked after and that the people here understand what it's all about. I run into so many people who think they know but they don't really know a thing. At least the people here do know. I'm quite happy because I looked after at home for three years and it was getting pretty tough and I know it's not easy. It's a 24

hour a day job so they're welcome to it. I know how hard it was. I could have looked after her for a lot longer but they said she should go into full time care because if it affected me then. It's enabled me to go back to work.

Comfort

Family member

Amaryllis are good in the sense of the chairs and the beds and the showering – they're quite strict on the showering. Hygiene is a high, which I'm grateful for...The carers are lovely people and I see it in their eyes and in the way they deal with people as well. Sometimes I go in there and I've got no idea how they're dealing with her but I look around and see how they're dealing with others and I get the feeling they must be treating her all right.

A return to normality

Family member

It's just taken complete pressure off me so I can devote my full time to my occupation. I probably would work a ten or eleven hour day and I couldn't do that unless I had her safely in a safe place. I can get on and do my job during the day and then see her when I've finished, or sometimes I want to go and see her and the convenience of it. I couldn't have asked for anything better really, just popping in on the way home whether it is for half an hour or three quarters of an hour, whatever time I like.

Family member

I said to my friends, for the first time in thirty years I know what it's like to feel normal, to feel like everybody else does. It was such a marvellous feeling, absolutely marvellous. For the first time in thirty years I didn't have the responsibility or the worry, the stress and the trauma.

Residents

It was difficult to ascertain the views of residents directly. The two who were interviewed particularly liked the outings, the company and the food. Family members and staff agreed that the activities and the food were popular. Other comments by residents and family members are included elsewhere in this report. Staff believed that residents also appreciated the safety and security Amaryllis House offers.

Staff member

I think the [residents] like the security, knowing what to expect because if their routine is mucked up or put slightly out of their normal sequence it can really throw them and the staff understand that now. I think they like knowing that they're in a safe place where they're cared for.

Staff member

I think in some ways they're quite pleased because we're a unit for Huntington's. They like that because everyone's in the same boat. If there's one who's difficult or needs understanding or is allowed to change his nap they know that it's not a problem.

Complaints

Staff residents and family members had slightly different perspectives on what concerned residents and family members. Staff again referred to food, and to small matters like the colour of bed linen.

Staff member

Occasionally, as much as they love their food they might complain about the odd thing about food but sometimes it can be something to do with a perspective problem that they've got. They've always eaten something then suddenly don't like it because it gives them a sore head or something. Or they got the wrong colour sheets on the bed, that sort of thing. Something that we've found really strange is that we've got two people who don't like red or anything red or burgundy. Just an absolute no-no. We have no idea why.

Residents had some concerns about personal care matters, like being fed rather than being able to feed themselves, in one case, and having to share a bathroom in another.

Family members' concerns reflected their anxiety and sadness at having to "put someone you love into other people's care". They worried about their family member's health, lack of consistency in approach, some carelessness about clothes and communication. Almost all prefaced their comments with remarks like, "I don't want anyone to get the wrong impression, everyone there is absolutely lovely and I love them all", and they all acknowledged that any complaints they had were addressed quickly once the families drew them to the attention of the management team.

One person who was concerned about their family member's health had asked for more intervention:

Family member

A couple of weekends ago I went in and he was really chesty. It was really rattly so I said, "I think he should be seen by the doctor and be on antibiotics because it doesn't sound good". I left a note for [the Manager] and the doctor was coming that Monday. Apparently his chest was clear but they gave him an antibiotic anyway. Last time I saw him he wasn't coughing at all. He must have needed the antibiotics. If he'd been at home he would have been at the doctor two months previously.

Another wanted her family member's preferences acknowledged:

Family member

She hates terms of endearment. "How are you today, dear?" "How are you, darling?" Everyone does it everywhere; it's just a natural thing. And yet some of the carers knew that and some of them didn't. Just the consistency, the basic coming together for your staff meetings and making sure that everyone is on the same track.

Some had developed systems for buying replacement clothing residents, after finding their family member dressed in someone else's clothes:

Family member

At one stage I went there and she was in somebody else's clothes and I said, "I don't want this. What's the problem?" "Oh, she's short of t-shirts." I said, "Tell me so I know to buy them." Because I don't see her all the time I don't see what she needs. We've got a good system going now with a notebook in the top drawer. If she requires anything special they write it in the notebook then whenever I go, I just pick up the notebook and take it away and get stuff when I want to. And they will label stuff for us. They are very hard on clothes because they've got to wash them and put them through the dryer so I tend not to buy quite expensive clothing. I used to and really it was just getting trashed.

One found that the towels had not been replaced in their family member's bathroom, but that and other matters were addressed once she raised them with management.

Family member

I went in and I went to the loo and there weren't any towels or anything, just a flannel on the floor. I said, "Did you have a shower this morning?" And he said, "Yes." I said, "What did you use to dry yourself?" He said, "Oh there wasn't any towel so I just used that flannel." And I thought this isn't on. There were some other things happening too, quote a list. We had a meeting with [the Manager] and she agreed that the different situations were not on and something would happen. As it happened, all those incidents revolved around one person. She'd only been there three months and she'd never had any experience looking after people with HD.

One family member, who lived some distance away, would like the staff to initiate more communication, partly because they would then be able to choose a time that suited them.

Family member

I would like more emails. I'd like a bit more of everything. I'd really like a phone call once a week. I'm thinking that they need to try and ring me. I do ring them quite a lot but they know when they are able to have that time to ring.

Aspects of the service that could be improved

Almost all the comments people made referred to the design of the building rather than to the care provided to residents and the support offered to family members.

Staff comments

Staff were much more likely than family members to comment because they spent much longer on site.

The main room

They were particularly concerned about noise levels in the main room, which they attributed to the high ceilings and hard surfaces.

I think on the whole the building works really well. There's just the odd little thing they could have improved on - maybe not having quite such a high ceiling. It's very noisy. The kitchen's right there.

Noise and heat would be the worst. And they're all crammed in. At times I look round and I think, gosh it reminds me of the days in the geriatric rest home where they were all sitting around.

Our kitchen is quite good but it can be quite noisy too, being a high stud and hot. When they're using the machines for their food and residents are sitting in there. It's probably too much. One of them sits there with his hands over his ears with the electric knife going. It's done in theory so it's like your home - you've got your kitchen, your dining room, your lounge, but in actual fact there's too much happening in the room.

Reorganise the TV which we're going to do anyway because that was not very well designed where the TV is.

Change the lounge arrangements

Both staff and family members had views on what lounge arrangements would be best. They agreed that the three small lounges were not used as planned, but still wanted some options for privacy for residents and their families. Another suggestion was to have two smaller lounges rather than one big main room.

Instead of having a different lounge in each wing [it would be good] if they had another big lounge that you could go into. Or even where we've got the recreation room at the side of the lounge - if that had been bigger and been the lounge and you had a recreation area at the end of the dining room, it would have cut off a bit of the noise.

Maybe have a bigger lounge type area. None of them like the little lounges. It's like a family of 14. They like to get together; they don't like to be on their own. We've got one or two residents that spend a bit of time in their room, but most of them come out. We didn't think we were going to have everyone in the main lounge but they all go there because of the action.

You've got a hoist and wheelchairs in the spa room there. It's a big area that's used basically for equipment.

Rethink the laundry arrangements

One suggestion was to rearrange the laundry services to reduce the noise and the amount of walking staff had to do.

There's a laundry right off the dining/kitchen area so you're going backwards through there with laundry skips and dirty washing. You've got machines going, the dryer going in there all the time.

They could have linen cupboards in every wing and a cupboard where the dirty linen can go because we have to stack it all in one room and I don't think that's nice and tidy. It would be easier for us and then we wouldn't have to be rushing. You have to do a lot of walking to and fro. A male may have designed it without seeing our input. You get a bit squashed in there too because we haven't really got much room.

Separate bathrooms

Residents, family members, some staff and support service staff were critical of shared bathrooms. That caused some distress to some residents and their family members.

Family member

That is the only fault – that some of the rooms have not got their own bathroom. He's got a lovely room with a lovely outlook but the shared bathroom is a problem. I think every room should have its own small toilet, shower and basin.

A whanau room

Another suggestion was for a room where family members could stay when their resident was very ill or dying. This room could be used for other purposes as well.

You need a whanau room when residents are going through that stage of passing on, where family members could stay. Hospitals and hospices have that now. We're using [a lounge] at the moment as a whanau room but there's no door. You need somewhere private, where they can have their own little cook ups and whatever. We need a self contained place. It would be good to have a whanau room.

Develop the outside

Staff found it frustrating and difficult to take residents outside.

The outside is not suitable at all. We've got more room at the front for people and at the back we haven't got much room at all. We did try to take the residents outside and encourage that but we've got a little triangle sail that doesn't protect them from the sun that much and the grass is full of weeds. The back area has never been laid out as it was originally supposed to have been. There's a water feature there. It's lovely but it's always broken. Unless we physically take them out they don't make an effort to wander out. And when we bring them out we have to have sun hats and there's a big table right near the doorway. You've got to try and wheel all these wheelchairs around on the grass. It's very difficult to

run activities outside because it's quite narrow. You've more or less got to go to the park or out in the community to do that.

The van

The other concern was the condition of the van, which is absolutely essential in providing the outings that residents and family members value.

The van, our van, it, it's shocking! It's too low and we've got tall clients in our facility. When we get the wheelchairs in they can't see out the window. All the other facilities have got flash vans and we've got this old thing that came from the Wairarapa. It's a shame because we try and get out in the community quite bit. I find the van unsuitable because we have got a lot of wheelchairs but we've also got quite a few people who are more alert and want to get out.

Family members' comments

With the exception of the call for separate bathrooms, family members had very few suggestions for change. One of those who lived further away wanted more small details about how her family member was doing.

Family member

I don't think the carers are empowered enough to talk to the family. The managers are the ones with the know-how and expertise to answer all the questions. Sometimes I just need to know the most basic things, like "How much did she eat?" or "Has she smiled" or "What television programme did she watch?" I did talk to the managers about that but basically the idea was that, "We don't encourage that because we believe that the managers are the ones who should be liaising with the family".

The things that made Amaryllis different at the beginning have to be re-established every month, every day even. Like let's look at everyone separately again. Let's not assume that someone can drink from a straw. Let's try a Tommy Tippee cup or whatever. Let's be flexible here, don't get set in our ways of thinking.

Comparisons with other services

Two people who had family members in services in cities outside Wellington described their experiences. While they were not familiar with the services offered by Amaryllis House, they could clearly see the benefits of having a dedicated service. Most of the families with a resident in Amaryllis House had also experienced other services. They had absolutely no doubt about the comparative merits of a dedicated service.

All of those who talked about other services described situations where the physical care was poor; where staff tried to make residents fit in with the institution's routine and where they simply did not understand about HD. In every case they saw Amaryllis House or a similar facility as preferable.

The remainder of this section illustrates the experiences family members had.

Family member

It was awful. It just was the wrong place. It was a psycho geriatric ward with all these much older people and people eating food down on the carpet and standing there and weeing. It just smelt, it was awful. And I didn't feel as though there were enough staff there.

Another had experience of several rest homes before coming to Amaryllis House.

Family member

Mum was in one rest home and they moved her to another. What happened was she was really aggressive and lashed out. She thought that they weren't pulling their weight or something riled her and she lashed out with her walker to people's legs. They were scared that she would lash out at another resident. But that wouldn't have been the case because she basically stayed in the vicinity that they put her in. She didn't go walking round hitting people or anything. In fact she loved the residents.

It was a very traumatic move. For some reason they moved her in the middle of the night into a dementia wing, because that was the only bed available. It was a horrible experience. The dementia wing in the new rest home had no en suite, tiny rooms, tiny bed, and no view or anything nice to look at. And you would go in and it would smell like a public toilet. It was just a horrible un-homely type of place and the food wasn't good either. Physically she became very bad. She almost lost her walking, she had many falls. I would get there and there would be big bruises all over her and it would just break my heart.

The rest homes don't fully understand the position of family where you waver between being incredibly emotional and putting on some sort of professional hat in order to deal with all the different strangers that are now your Mum's closest people and they remain that to this day.

Those who did not have Amaryllis House as an option were struggling to get adequate quality care for their family member. The case study below describes one man's efforts of behalf of his mother.

Family member

She went into the first rest home and they looked pretty good to start with. Their head nurse claimed to know a little bit about HD but really they didn't know anything about it. She was there for six months or so. At first she was in just the standard room with lots of old people and she was doing pretty well there. Then they found her a little bit difficult because she'd sometimes go out on the road and stand and wait for me or Dad to come. It was a main road and they were concerned about her safety. So the call was made to put her in the secure part where she had a little room that opened out into a courtyard. Obviously the people in there were slightly different and that's when I think the trouble started because the staff did not know how to handle her whatsoever. They argued with her and they would do everything that you just can't do.

Then they said they thought they would have to move her onto safe support care. I was not happy with that because the home that she was in was in her part of town and it was easy for Dad just popping in and all those little things. But they moved her without telling me by saying they were going for a drive. They basically took a few of her possessions like a photo and a change of clothes and left her in the new place.

She's in an aged care dementia place. She's got a nice room but it's an old age facility. I don't know if the staff know that much about HD itself but they know how to handle people that are not well. Although having said that, it's not the right place for her either.

She doesn't need to be in a stage four care facility. She needs to be in a place where they understand her. She's in a secure unit now but she can get out to a garden and the staff there have been better in terms of trying to come up with things that she can do, like gardening. She's still walking and she still carries her meal down to her room because she won't eat in the main room. They said that she's really unsteady on her feet and they are concerned about her but they let her do it.

It's having the people that can look after Mum in terms of her personal care. Not everybody they get in knows how to handle people like that. That's probably my main problem - giving Mum some quality of life in doing those things.

A daughter has similar challenges in trying to maintain her mother's well-being:

She has a purpose built chair that we had changed around a little bit. It had everything. It opens right out to a single bed basically. She's into sliding. She can't sit in a wheelchair otherwise she'd slide down all the time. And she's quite strong through the hip area and will pull herself up through the hips. Getting the staff to try and understand that we're trying to change the chair so that it stops her from sliding. I've probably been doing it for the last year and a half going, "How about we try this?" And they go, "Oh yeah, yeah." You work your butt off trying to get the modifications done and then you ask them and they say, "Oh yeah, it's okay." "Is it helping you or isn't it?" The chair can do anything. The sides come down, everything. They don't use it how they should.

And I am never happy with her personal care. Every visit I go and do her hair, I wash her face. And that's what I hate. It's because that's the job of another

person - to look after her. But they don't. They're not doing it because they want to, it just another job. That's the impression you get. You get frustrated and I try not to get angry because I'm always afraid that they'll take it out on her and she can't tell me. There was an incident today. She's got a burn on her arm and I'm like how did that happen? I'm assuming it was from the time they put one of the heaters close to her chair and she's put her arm on it and burnt it. I'm like, "How thick is that?"

For all that, this family member would not send her mother to Amaryllis House because it is too far away. She would like a similar facility in her city so that she could still visit her mother as often as she needed or wanted to.

I think if we had a place, it would just mean that people understood. They'd know what the disease is all about and do the right cares for her. She could possibly have been involved in a lot more activity. She would have a better quality of life.

Conclusion

The interviews and analysis carried out for this report sought to assess the quality of the Amaryllis House service model and the value it adds for residents and their families.

It is apparent that Amaryllis House achieves its goals very well. It provides a secure, safe, homely environment for residents and a sense of security and a welcoming environment for family members.

The remainder of this section addresses each of the research questions.

Does Amaryllis House function as a “home”?

Amaryllis House functions as far as possible as a home, but still retains some elements of an institution.

The extent to which Amaryllis House can function as a home is constrained by the health and condition of residents. Some have extremely limited mobility; some cannot communicate their wishes or make decisions; others are unsafe going away from the House unaccompanied. Staff have to balance the desire to give residents as much control as possible with the need to protect their safety and ensure that they are appropriately cared for and fed. Family members fully recognise these constraints.

Does Amaryllis House support the principle of “normal living”?

Amaryllis House fully supports the principle of “normal living”.

The management team at Amaryllis House is exemplary in providing leadership in this regard. They fully understand and support the principles that underpin the service and make every effort to ensure that these are maintained. They do this by ensuring that meeting the needs and wishes of residents is the first priority. They ensure that any issues that residents or family members raise are addressed quickly. They make family members feel comfortable in raising issues that concern them and they engage in and support staff training. They discuss issues as appropriate with individual staff.

Having two managers has proved beneficial. Amaryllis House is the type of service that requires constant vigilance and management expertise. With two managers, someone is always available to make decisions, provide oversight and ensure consistency.

Both managers acknowledge that it has taken some time, patience and persistence to bring all staff on board with the new model. Most staff have worked in other services or hospitals that operate on a more regimented model, with residents having to fit into the institution routine rather than the other way round.

Does Amaryllis House offer a range of support services that provide clients with choice and decision making opportunities?

Amaryllis House offers a range of support services but clients have limited choice and correspondingly few opportunities to make decisions between services.

All those interviewed agreed that there is a good range of support services available, but not necessarily a choice of support services for clients. This partly reflects the availability of such services and the relationships that have established between staff and a particular service, and partly some residents' lack of capacity to know when they

need a service or how to choose among services. Family members were generally happy with the range of services and did not expect or particularly want to have to choose one over another.

Is there an appropriate level of clinical expertise available?

The level of clinical expertise appears to be appropriate, although timeliness can be an issue as it is for other people in the community.

It was apparent that some staff would like more timely support with managing the behaviour of some residents. It may be useful to explore ways to develop management strategies in preparation for a range of possible behaviour changes.

Other concerns centred round food. Amaryllis House does have access to the services of a dietician but timeliness is again an issue.

Staff have learnt from their experience in managing illness and death. They have developed protocols and consent forms for residents and/or family members to sign so that everyone is clear what the families want, and they have drawn appropriately on the expertise of other services such as the hospice.

Does Amaryllis House acknowledge personal security needs and allow clients to maintain their safety and dignity at all stages of the disease?

Amaryllis House recognises personal security needs and gives priority to safety. This can mean that the dignity of some clients can be compromised to a limited extent.

One of the changes to the operation of Amaryllis House has been the increase in security with locked front and back doors. At the outset, no one foresaw the extent to which residents might wander or want to leave the premises, either because they did not want to be there or because they wanted to visit someone, often at completely inappropriate times. This was particularly so with men, some of whom wanted to be at home and were prepared to take more physical risks.

The environment round Amaryllis House is not particularly safe. The grounds are not securely fenced and it is adjacent to a number of busy roads and to a railway line. In a facility that had larger grounds and secure fencing, it may be possible to operate with a lower level of security.

Does Amaryllis House operate in the way it was originally planned?

There have been two significant changes in the way Amaryllis House operates. One refers to the use of the house for respite care. The other refers to the use of the space.

The plan to use two beds at Amaryllis House for respite care has not worked particularly effectively. This is due in part to the high demand for beds for permanent care and in part to the reluctance of people who are at earlier stages of the disease to spend time in a facility where everybody else is, almost by definition, at a more advanced stage. It may be appropriate to consider developing alternatives for respite care, given the demand for both permanent and respite facilities.

The other change relates to the use of the building. This change was driven by residents' preferences but it does have implications for the design of facilities in the future.

Reviewing the way lounge or sitting space is provided could increase the flexibility of the living space and give more options for both privacy and recreation. It would also be beneficial to have a space that could be closed off and used as a whanau room or a room for visiting family members to stay in overnight when necessary.

Do residents and their families think that Amaryllis House offers a high quality and appropriate service? Do they see it as a centre of excellence?

Residents and their families do think that Amaryllis House offers a high quality and appropriate service. Most of those interviewed were unfamiliar with the concept of a centre of excellence.

Residents and family members were generous in their praise of Amaryllis House, especially where they had had experience of less satisfactory services. They particularly appreciated the responsiveness of the managers, the open home policy, the security and safety the facility offers and the ability they had to regain some level of normality in their own lives. No family members found it easy to admit that they could no longer care for their partner, son or daughter at home. None wanted to “hand over” their family member to others. Their ambivalence was evident both in their relief and in the feelings of guilt which they sought to alleviate through close oversight of the care provided.

Are there any aspects of the service that could be improved?

The fact that family members had so few complaints was an indication of the high quality of the service offered at Amaryllis House. Any complaints they did have were addressed promptly. None were systemic or of major significance.

The main suggestions were from staff who called for some rethinking of the building design and the use of space, as discussed above. They also made suggestions to improve their working conditions and make the physical management of residents, with their wheelchairs and other equipment easier.

Do families with people with Huntington’s disease in other residential facilities see these facilities offering as high a quality and appropriate service as Amaryllis House?

The research interviewed only a few families with people with Huntington’s disease in other residential facilities. They had limited knowledge of the services at Amaryllis House but were certain that the facilities they used were no match for a purpose built, specialist service.

Families with residents in Amaryllis House often have experience of other services and were in an excellent position to make comparisons. Without exception they found that these services did not come close to matching the quality of service offered at Amaryllis House. The staff were invariably unfamiliar with Huntington’s disease in all its manifestations and stages; the physical environment was often poor and personal care was not up to the standard they wanted. Relationships with staff and management were often poor and communication was unsatisfactory. Family members were placed in rest homes, sometimes in dementia units, and almost always with people who were much older than themselves and who, willingly or otherwise, fitted in to the institutional regime.

Do they have any comments on the advantages and disadvantages of having a specialist service?

Families could see only advantages in having a specialist service. The advantages included familiarity with the disease, an associated increase in staff skills and understanding, personalised treatment and care and good communication.

Amaryllis House offers such a specialist service with the resident at the centre. Staff are open to learning new skills and approaches, management is responsive to family members' concerns and the building and services are of a high standard. Even staff from other facilities recognise that. One has the last word:

I had a visit from one of our resident's friends who was a registered nurse. She was at [a private hospital] and she said, "My goodness, this is like a castle compared to there. It is terrible going there and coming back here again." She was quite overwhelmed at what is here.



Specialist Rehabilitation Services – Hutt Valley DHB

20 December 2007

Director General
Ministry of Health
P O Box 5013
Wellington

Dear Sir/Madam

Re: Amaryllis House, 1A Rodney Street, Lower Hutt

I am Dr Brian Peter Gregory Young, FRANZCP. I am employed by Hutt Valley District Health Board as a Consultant Psychiatrist and have worked in both psychiatry of old age and consultation liaison psychiatry. In both these capacities, I have attended to patients who have Huntington's disease at Amaryllis House. I have been consulted by the attending General Practitioner, Dr Chris Masters. I have previously seen patients with Huntington's disease referred in from other community facilities both during admissions on the psychiatric ward and when the occasion required, admissions into the general hospital. I have been extremely impressed by the care of patients at Amaryllis House. I have no doubt that the specialised interest that staff at Amaryllis House are taking patients with Huntington's disease is of great benefit to those patients and their families.

I am writing this letter in support that facility in the hope that the Ministry can continue to provide such a facility for these patients. Please do not hesitate to contact me should you require any further comments.

Yours sincerely

(Electronically signed and approved)
Dr Greg Young
Psychogeriatrician

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