



Effective housing and support models for people with Huntington's disease

Report 2: Interviews with close others

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Please note that these are preliminary findings and are correct at the time of publication. Full findings will be published following completion of the project.

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Executive summary

Background

Huntington's disease (HD) is a genetic neurodegenerative disease that affects global executive functioning and includes cognitive, physical and psychiatric symptoms. Housing and support needs of people with HD change as the disease progresses. In Australia, people with HD often end up living in residential aged care (RAC) facilities, even when aged under 65 years. Although the Australian Government has set targets to ensure that no people under the age of 65 years are living in RAC by 2025 (DSS, 2020), it remains unclear what housing and support models are effective for people with HD. It is particularly important to understand how National Disability Insurance Scheme (NDIS) funding can support people for the duration of their lives and avoid admission to RAC. In the absence of an evidence base, the aim of this research was to explore housing and support for people with HD from the perspective of close others (i.e., family, friends) of people with HD.

Method

Qualitative interviews were conducted with 11 close others of people with HD in Australia who represented 16 people with HD. Interviews were recorded, transcribed verbatim and analysed using open, axial and selective coding.

Findings

Four overarching themes related to effective housing and support models were identified:

1. Experiences with Housing and Support Models
2. Experience with NDIS and NDIS Funded Supports
3. Key Elements of Housing and Support Requirements for people with HD
4. The Role of Advocacy

Overall, participants described a lack of choice and availability of appropriate residences that could house the individual with HD for the duration of their disease. Those who lived in RAC experienced isolation, poor levels of care and sometimes injury through a lack of available specialist support. Participants described the importance of HD expertise in health and disability support teams, long delays and a lack of expertise in the NDIS and disability sectors and a need for a system that is fit for purpose for people with HD to live in housing that meets their needs and preferences.

HD-specific facilities were reported to be a potential solution by some participants; however, problems emerged with design and the cohabitation of people at different stages of the disease. Participants described the following key elements of housing and support that are crucial for people with HD: design that will be physically accessible across the disease trajectory; options for location near existing community; home-like environment; expert health and disability supports and access to outdoor areas.

Whilst the introduction of the NDIS has been beneficial for people with HD, interview participants reported that the NDIS is not fit for purpose for progressive neurological conditions. People with HD remain excluded from contemporary housing and support options through a lack of timely and adequate funding, lack of housing that meets their needs throughout the dynamic course of their disease and a lack of expertise in HD across NDIS and disability support services.

Close others experienced carer burnout, limited or no counselling to accompany diagnosis, limited respite, and difficulties in accessing and understanding information on HD. Participants reflected on their informal advocacy role and the constant need to be the voice for the person with HD, seek better support and challenge funding decisions.

Implications

The housing and support needs and preferences of people with HD are complex, dynamic and can change with little warning. Early in the disease and/or when the person with HD is living at home supported by family, there is a need for expert health and disability supports to ensure that this arrangement remains sustainable. This includes allied health, positive behaviour support, education and psychological therapies for caregivers. There is a need for housing that can support individuals throughout the trajectory of their disease (i.e., a combination of robust and high physical needs housing). Housing stock should be available to people in locations that are close to existing communities irrespective of their metropolitan, regional or rural status. Where communal housing models exist, there should be consideration of the built environment (i.e., a home-like environment, access to outdoor areas) and the impact of living with others with more advanced disease can have.

Disability and health supports should have expertise in the unique symptom profile of HD and match their support provision accordingly. This includes training in positive behaviour support, motivational strategies and provision of care that meets the individual's needs whilst continuing to encourage independence. The NDIS should provide a funding model that adequately reflects the housing needs and preferences of people with HD with flexibility to direct funds where they are needed when the person's needs change unexpectedly. Given the unique complexities associated with HD, it may be necessary to dedicate specifically trained NDIS planners to ensure that NDIS plan development and implementation are done in an effective and efficient way.

A greater need to support close others was identified with specific references to carer burnout, counselling to accompany diagnosis, increasing respite options, and ongoing education and psychological support. Regular and manageable information could be provided upon initial diagnosis, subsequent gene testing of other family members, and follow up information to meet the changing information needs as the disease progresses.

As informal advocates, close others require greater guidance on how to navigate the complex NDIS system, gain upgraded supports and timely specialist advice/assistance. In the absence of adequately skilled support coordinators or dedicated planners with HD expertise that can spend the time needed to coordinate the complex interfaces between disability, housing, hospital and RAC sectors, it may be useful to engage specialist services to meet this need in the interim.

Background and aim

Huntington's disease (HD) is a fatal genetic neurodegenerative disease. The disease is rare, affecting 7.5 per 100,000 in European, American and Australian populations (Rawlins et al., 2016). It affects global executive functioning and includes cognitive, physical and psychiatric symptoms that worsen progressively (Layton, Brusco, Gardner, & Callaway, 2021). The general age of onset is 30-50 years and the prognosis from age of diagnosis to death is around 17-20 years (Myers, 2004). Due to the complex nature of HD, people often require various supports, including housing. They require support from a specialised multidisciplinary team, including neurologists, psychiatrists, occupational therapists, psychologists and speech therapists.

The National Disability Insurance Scheme (NDIS) is an Australian Government scheme that funds costs associated with living with disability (NDIS, 2021a). The scheme entitles people, referred to as "participants", with permanent and significant disability and are aged under 65 years to funding for any "reasonable and necessary" support needs related to their disability (NDIS, 2021b). Funding is allocated to the individual, and the individual or their guardian chooses which providers supply the funded goods and services. Specialist Disability Accommodation (SDA) is a range of NDIS funded housing designed for people with extreme functional impairment and/or very high support needs. Supported Independent Living (known as SIL) is an NDIS funded support that provides help and/or supervision around daily tasks including personal care. With 945 NDIS participants with HD in March 2021, this cohort comprises a small proportion of (0.21%) people receiving NDIS supports (NDIS, 2021b). As a proportion of the general population who are NDIS participants, the rate for people with HD is very low at 3.9 people per 100,000 nationally, although the rate varies between states and is greater in South Australia and Tasmania (6.5 and 9.3 per 100,000 respectively) (NDIS, 2021b). Most NDIS participants with HD are aged between 55-64 years (35%); however, 31% are aged between 45-54 years, 16% are aged between 35-44 years and 8% are aged 34 years or below. Ten percent of NDIS participants with HD are aged over 65 years. Seventy nine percent of NDIS participants with HD are gauged to have "low level functioning" compared with the broader NDIS cohort at 27% (NDIS, 2021b). There is a roughly even gender distribution with 52% of NDIS participants with HD identifying as female, 47% as male and 1% as other (NDIS, 2021b). Sixty nine percent live in major cities, 30% in regional areas and 1% in remote and very remote areas (NDIS, 2021b).

In Australia, people with HD often end up living in residential aged care (RAC) facilities, even when aged under 65 years. Recognising the inappropriateness of aged care for young people with disability, the Australian Government has set targets to ensure that no people under the age of 65 years are living in RAC by 2025 (DSS, 2020). Whilst there are housing facilities specifically for people with HD, there are very few places available in Australia (housing for 62 individuals: Australian Huntington's Disease Associations, 2020). Five Huntington's Disease Associations (HDAs) in Australia collated information surrounding existing HD designed facilities that have higher staff ratios than RAC. Combined, there are 4 HD-specific facilities in 3 states; the largest facility is located in Victoria, housing 36; the NSW facility is affiliated with a hospital, housing 14; WA has 1 small capacity facility (where 6 people live in a supported community house) for early-stage HD; and a larger capacity facility (12 people) for people with later stage HD who have higher care needs (Australian Huntington's Disease Associations, 2020).

With a few possible housing and support models for people with HD, it is important to understand the effectiveness of the models and who they work best for. It is particularly important to understand how NDIS funding can support people for the duration of their lives and avoid admission to RAC. A scoping review of the international literature was conducted to understand the most effective housing and support models for people with HD (Cubis et al., in prep). This scoping review demonstrated that although there were 7 studies in the area of housing and support for people with HD, few acknowledge the caregiver's perspective regarding effective housing and support models for people with HD. In order to do this, new qualitative research was conducted with people with lived experience of HD as a close other (e.g., spouse, family member). Additionally, interviews were conducted with professionals who had expertise in housing and support for people with HD (these are reported in a separate report).

The aim of this research was to explore close-other perspectives on the effectiveness of housing and support models for people with HD, including those who have provided support to family member/s with HD.

Method

Participants

Ethics approval for the study was obtained from La Trobe University ethics committee. Potential participants included family members and/or close friends of people with HD in Australia. Potential participants were identified through a number of activities: 1) networks known to the Summer Foundation's Research Team; 2) people identified by stakeholder reference group members and Lived Experience reference group members; and 3) potential participants who responded to an advertisement circulated via social media. Each participant was provided with the plain language statement and consent form. If they were interested in taking part, they returned the consent form to the researchers and a time was organised to conduct an interview via telephone or Zoom. Interviews were approximately 50 minutes in duration and were audio recorded and subsequently transcribed.

Data collection

Interview questions focused on current and past housing and supports; positive and negative experiences with housing and supports; ideal housing and support models and ways the NDIS can best support people with HD with housing and disability supports.

Data analysis

The interviews were professionally transcribed and read by 2 researchers. Thematic analysis was used to analyse the data from the interviews. This method was selected to identify, analyse and report patterns within data (Braun & Clarke, 2006; Braun et al., 2018). Two researchers read through the transcripts and identified possible codes. Transcripts were then re-read to examine the suitability of these codes to the data more broadly. The codes were used to generate broader themes.

Results

Qualitative analysis revealed 4 interrelated themes:

1. Experiences with housing and support models
2. Experience with NDIS and NDIS funded supports
3. Key elements of housing and support requirements for people with HD
4. The role of advocacy.

These themes and associated sub themes are presented below.

Experiences with housing and support models

Close others of people with HD described their overall experiences with navigating housing and supports as being characterised by a lack of choice which often resulted in people spending a long time stuck in hospital and/or RAC due to an absence of housing options that met the complex needs for people with HD. These unmet needs related to both housing that was designed for a person with HD's physical support needs, as well as the presence of disability and health support staff to meet the complex physical, cognitive, psychiatric and behavioural needs of the person with HD.

Interactions with the health system and health professionals were considered an important component that could greatly influence an individual's journey through the health system and access to funding for appropriate housing and supports. Some participants described the pivotal role of a hospital social worker in advocating for a person's housing needs and preferences needed.

An initial and important connection for caregivers was with advocacy groups, such as HDAs. They could provide advice on referrals to HD clinics and specialist equipment that can aid in care including specially designed HD beds and chairs. In some instances, the social worker assisted people with HD in securing housing.

“...the social worker got him into the house. She was magic. She did in three weeks what other people couldn't do in five months.” (Chloe)

Participants often described experiences of poor quality of care characterised by a lack of expertise in the unique and dynamic support needs of people with HD. An absence of available options outside of an aged care setting meant that rather wishing for models underpinned by person-centred practices and principles of choice and control, many close others expressed low expectations for the “best case scenario” by expressing that they simply want somewhere that their family member is safe.

Participants described a variety of housing and support models that they and their close other had lived experience with. These included living with family; HD-specific facilities; RAC; extended hospitalisations; and NDIS supported housing.

Living with family

Many close others reported that the person with HD had a preference for remaining at home with family. Where this occurred, participants described a significant shift in role from spouse or family member to that of carer. Further adjustments included the introduction of paid support workers in the home. As the disease progressed, caregivers reported that worsening functional status as well as increased behaviours of concern presented challenges that they felt ill equipped to deal with. In addition, close others reflected on how the changing behaviour of the person with HD impacted them personally. For example, 1 participant described persistent personalised negativity from a person with HD; the physical and mental toll this had on the family member resulted in the necessity to seek alternate housing. Others acknowledged the elevated stress associated with being a carer and the physical toll this can have. Five participants reported substantial financial implications as they were forced to fund private care and other supports or reduce their hours of primary employment to provide care.

Close others reported critical gaps in their knowledge about and capacity to manage behaviours of concern (including adynamia) and physical symptoms such as muscle spasms and involuntary movements. In some cases, the person with HD reportedly experienced substantial health effects due to a refusal to engage in activities of daily living such as teeth brushing. The cognitive effects of HD often resulted in rigid thinking, paranoia, verbally abusive behaviour and a lack of insight into the person with HD's need for increasing support. The impact of these psychiatric and behavioural symptoms on carers was discussed by many participants, often leading to a breakdown in family relationships.

Olivia discussed the difficulties in dealing with the behavioural effects of HD: "...the behaviour is the big one I think for most HD families and he has become very paranoid". Constant, extreme verbal and emotional abuse impacted Olivia's personal capacity to cope; "I gradually came to agree that yeah, we needed to live under separate roofs. Or otherwise, I'd end up in a heap".

Caregiver capacity was also noted by Sophia in relation to understanding the complexities, progression and presentations of HD:

"So to be able to have a better understanding of them or their behaviour issues or their outbursts, their involuntary spasms and movements, if you don't know anything about that and you're not trained in that area it's hard to actually support that person with that disability or that disease."

Caregiver burnout, and the need for respite was highlighted by participants. One participant discussed the benefit of family/carers taking time for themselves (away from the person with HD) through short breaks; "I highly recommend it to just go out and have some peace. For a couple of days or a week" (Olivia). The need for respite for carers was echoed by another participant stating, "So just getting more services for families and more respite 'cause my [sibling] and myself were restricted in what we could do and where we could go because we always had Dad" (Sophia).

It was important to have confidence in the respite providing “a high-quality service” to mitigate concern among caregivers; especially those who had experienced previous negative incidents or if the temporary change in housing created distress for the person with HD:

“...we would put them into respite and my mum wouldn’t cope or my dad was missing my mum ‘cause they would separate them. ‘Cause Dad had Huntington’s, Mum had dementia, they wouldn’t put them together so then that brought on distress so then they’d only last two days and then we’d have to pick both of them up because they wanted to be together. It was yeah very hard.” (Sophia)

Maintaining the family unit within the 1 house was viable under specific circumstances including the stage of the disease and availability of supports. In 1 situation, the couple moved together into a retirement community. This allowed them to draw on the community as supporters:

“it’s a low-set house, and – and he’s able to cope with the bathroom and toilet there and everything else. And the community is close by, we have support close by in - in the neighbours, yep.” (Isabella)

Some participants acknowledged that a day would come where the person’s needs would progress beyond the capacity of the current family home and will require formal supported living. In order to make living at home viable, there was a need for paid support workers as well as informal supports to ensure that needs were met across physical, psychological and social domains:

“So we envisage that her support workers will come here at a time when she will need help with personal care and things. I don’t want her to be isolated here. My husband’s semi-retired but I still work three long days a week. Like I’m out of the home for 11-12 hours, so the last thing I want is for her to be stuck here. She’ll have supports come and take her out, so I’m sure that will be fine. So hopefully that works for a good few years. But yeah it’s the social side of it. It’s the loneliness and the depression. That side of Huntington’s that...she doesn’t need 24-hour care, but she needs people around her.” (Grace)

This sentiment was echoed by William who wanted to maintain a homecare arrangement for as long as possible:

“I just traditionally with [our culture], it’s like, we don’t sort of put people in nursing homes, we care for them up until they sort of pass away, sort of thing. You know? And I guess, unless it gets impossible for me to look after [person with HD], I don’t really intend to put her in a nursing home, even if there – there was places like [organisation] and that sort of stuff, that are for the younger people with disabilities and that, I just – for her sake, I know that... this is what she wants and I’ll do what I can to provide for her...” (William)

Supporting a family member with HD was impacted by the rapid development and progression of symptoms and subsequent change in family roles and physical needs. For some caregivers, worsening symptoms was the trigger to seek alternate housing for their close other. Several participants (Emma, Olivia, Layla, Ava and Chloe) described the change in family dynamics as the symptoms worsened for the person with HD and the impact this had on their capacity to provide adequate care. Adult children or siblings observed the deterioration of close others whilst living in the home resulting in changes to domestic duties and taking responsibility for determining the next level of care.

In 1 situation, the decision to move a person with HD out of the family home was made by medical staff: “they refused to let him back into my care” (Chloe) but finding more suitable housing for a young person with HD was the responsibility of the family. When the person with HD needs to move into a more suitable facility in a timely manner, family members are then often faced with a lack of housing choice in close proximity. This frustration was explained by Harper:

“So, we had to try and find housing for him. Because at that stage he was only 47, so no nursing homes would take him. And with social workers – and even my [family member], she works for [disability organisation] and she tried to find places but the nearest one she could find was on the other side of [City], which is like a 25-minute drive. And that was just too far away from me.”

HD specific facility

Two participants had experience of their close other with HD living in an HD-specific facility (i.e., a facility designed and staffed for people with HD and/or similar neurodegenerative conditions). These typically included groups of people with HD living in the same facility with their own bedroom and bathroom and communal areas. The primary perceived benefit of this model was that the staff had a higher degree of expertise in HD as a function of working in the facility. There was also often better availability of a multidisciplinary team with HD expertise.

Notwithstanding these perceived benefits, participants described a series of downsides to these HD specific facilities. HD specific facilities were often described as resembling a hospital or RAC facility more than a home, and therefore were not appealing places to live or for family and friends to visit. Physical attributes included a sterile environment and lack of warm furnishings. Further comments on these facilities included that when care staff took over all of the activities of daily living (ADLs) for a person with HD, they experienced further functional decline as a result of loss of practice. In 1 case, this resulted in such severe loss of motivation that the person with HD did not leave their bed any longer:

“So there's no reason for her to get out of bed. Because there's nothing that she needs – like, you know, a bowl of cereal is – is brought to her room in a bowl.” (Mia)

Despite a hope that HD-specific facilities would enhance social connection opportunities, it was evident that the environment, populations and often the geographical location further contributed to loneliness and isolation. Some participants reported that entering these facilities could be confronting for families and, indeed, for the person with HD themselves when faced with other people with more advanced HD. This disparity between stages of disease meant that for some people with HD, they could not form relationships with other residents. In the below quote, the person with HD was at an earlier stage in the disease than other people living in the same dwelling. As such, the participant felt that a staged care model would have been more appropriate, where people live with others at a similar stage of functional capacity:

"Because my sister's the only one verbal in her house. So there's not even anybody else that she can speak to other than the staff." (Mia)

Residential aged care

In many cases, the only housing option that would accept a person with HD was a RAC facility due to the availability of 24/7 care and access to nursing staff. This was particularly prevalent for persons diagnosed with HD after 65 years of age, if diagnosed pre-NDIS, or where the family living arrangement was not suitable when immediate high-level care was required. Families reported that the lives of people with HD living in RAC were characterised by isolation, neglect, injuries, abuse and functional decline.

The age and life stage of family members and their capacity to care for the person with HD can lead to placement in RAC:

"We were really young when she went into a nursing home so we couldn't take care of her...you know... back then... and she really only needed to be in a nursing home the last I'd say five years realistically... but she didn't have anyone to care for her." (Emma)

RAC facilities were not considered to provide sufficient stimulation or behavioural support for a person with HD. Individualised care or recognition of a person's needs was dependent on individual staff members taking an interest.

"...look it really depends on the staff that are working there to be honest. Like, as of late where she is currently residing, there's been a couple of really great young and enthusiastic staff members that have tried to do things like you know putting in a Google Home in her room because they know she likes music. So they'll go in and they'll put music on for her you know they've try to allow for extra one on one time (with staff time to clean her nails)." (Emma)

Two participants discussed the decline of their respective family members with HD as a direct consequence of being placed in RAC too young and still cognitively functioning (Emma and Ava). Similar to those living in HD-specific facilities, people with HD who lived in RAC experienced loneliness and isolation. This was, in part, through living in an environment that was filled with people of a much older age group as well as being confronting for visitors. Even in RAC facilities where staff made a genuine effort to engage the person with HD, an environment and activities tailored to a much older demographic resulted in them becoming withdrawn and inactive.

“She hates it, she is really unhappy. She always has been unhappy being in a nursing home because you know like she always says, ‘I’m not old’. When she kind of went into the nursing home we saw such a shift in her because she became quite a recluse and so she would never leave her room. She didn’t want to participate in anything with the other residents because in her eyes she’s not like them.” (Emma)

“...when you see him in the nursing home...he’s pretty confined to his bed...he won’t get up and participate in any of the activities that are there. Because it is all, you know old time music and it’s not AC/DC and Metallica and you know. I mean the staff do their best, they get him up and they take him for walks and they put on his iPad and listen to you know his music and stuff like that but it’s very limited.” (Ava)

Participants also described their close other experiencing poor quality care in RAC due to a combination of inadequate staff ratios and a lack of specialist knowledge in HD. Although training was sometimes offered and provided by HD peak bodies, participants reported that this did not typically result in the implementation of better care. This was in part attributed to high turnover of staff and those deemed skilled in working with people with HD being moved into other positions.

“It’s really lacking in insight. That’s – they’re clueless. Totally clueless. And I don’t understand ...they’re meant to be trained professionals.” (Harper)

In some cases, this lack of specialised care and adequate supervision had alarming consequences:

“She has now had two falls in this nursing home...She’s fractured her back and her collarbone because she has gotten up and fallen and people haven’t attended to her quick enough because she needed to go to the toilet, and nobody came.” (Emma)

Consequently, 1 participant had developed anxiety and exhaustion from the poor level of care her family member was receiving “I get so upset by the home because of the way they’re failing her, I find it so difficult to go there” (Harper). The family member reported that they had to take responsibility for taking the person to hospital when one serious fall happened,

“Like I had to take her to the hospital the other night because she fell back and hit her head and even though she had her helmet on she had a very bad haematoma on her head. And the nursing home has also failed in this area because they pressured me to take her to hospital.” (Harper)

The seriousness of falls, hospital visits and inadequacies taking place over the years resulted in 1 close other reporting concerns to the Royal Commission.

“She – every time I went in there, she would be wet on her clothes and she would be covered in food. So all they have to do is give her a sippy cup and put a bib on her. It is such a basic fundamental requirement for her human dignity, but they don’t do it. And when I ask somebody to do it – I have to fight for it. It doesn’t go down the line. To the point where I am sick from my anxiety because I have to fight for her so hard all of the time. And what’s the worst thing to me is they make the bed. They put the bed up to make it, but they don’t put it back down again [and she is small in stature]. She falls all the time. She has fallen out of bed. For my peace of mind, all I want them to do is to put the bed down. I don’t think that’s too much to ask.” (Harper)

While acknowledging HD places people at risk of injury, poor care received in RAC created additional consequences for close others deal with:

“...Dad was lifted up on a hoist and they ripped all his backside open and he had pressure sores. From that Dad never recovered. After coming home from respite, Dad was completely bedridden from thereon and had to have constant wound care daily... his actual backside had a pressure hole the size of your fist and it was that deep down to his tailbone.” (Sophia)

Apart from the concerns with training and level of care in RAC, participants described RAC being intolerant of people with HD, particularly the behavioural symptoms of the disease:

“...The nursing home said, ‘Well we can’t have her doing that to other residents.’ But it was directly related to the Huntington’s.” (Harper)

Alarming, some people with HD were not even accepted into RAC due to the complexity of their needs, meaning that people with HD were left with even less housing options.

“He was to go in. But the nursing home rang and said “Look, we are really sorry, but we can’t take him”. And I went, ‘What!’ I said, “He’s got the ACAT Assessment!” and they explained that their funding is according to what they had to do for each client.” (Olivia)

“We couldn’t get a place for her straight away in the nursing home. One nursing home that was close to home for me didn’t want to take her because of her Huntington’s. So that was very devastating.” (Harper)

Participants described the confronting reality they witnessed during visitation at a RAC facility. Family members would observe others in the facility with worse symptoms, including violence towards other residents. Chloe recounted an incident where she witnessed another resident assaulting her family member.

Overall, the following quote summarised how a close other felt about the young person with HD in RAC:

“Terrible for me. Terrible for him. He probably declined; well I know he declined quicker than he should have done. Very depressed.” (Ava)

One person with HD moved into housing close to a RAC facility with access to some of the supports offered by the facility without actually living there. This innovative solution provided the person with HD a level of independence but support at the same time.

Extended hospitalisations

In the absence of suitable housing options, some people with HD were admitted to hospital as a temporary measure. In some cases, people with HD were in hospital for many months due to a lack of housing and support matching their needs and preferences:

“He sat out in [regional] hospital for about five months until they suggested that he move an hour closer to us in a nursing home in [regional town] ... he was there for about three or four months and [we] didn’t really hear too much from disability... they more or less said well he has to be ‘ACAT-ed’. We don’t have a place for him so the only solution was to put him into aged care” (Ava)

“...he was in hospital for four months waiting to go into something that [could look after him] because I could no longer keep up with the whole personal care, everything, 24 hours a day, seven days a week.” (Layla)

“...there’s three residents there that have been in the hospital for nearly a year now because they can’t find suitable housing or they don’t have anyone to advocate for them ... to find suitable housing or nursing homes just aren’t the right fit.” (Emma)

Hospitals are an immediately available form of safe ‘housing’ for people with HD who are experiencing a rapid onset of worsening symptoms. In Mia’s experience, hospitalisation provided her close other with the opportunity to have medication regulated and stabilised. Although a positive experience, hospitalisation is not a viable long-term solution and COVID-19 reinforced the need to find more suitable housing and Mia accepted the only option available.

NDIS funded housing and support

Some participants resided in NDIS SDA and/or had NDIS funding to provide supervision, personal care and any other support for completing daily tasks. The process for applying for funding under this model was described as arduous and time-consuming meaning more time spent in RAC or other inappropriate housing settings:

“...so that was probably two years ago so we’ve watched that being built and for the last six months we’ve been having team meetings with my NDIS coordinator and his plan manager and it’s been mammoth. He hasn’t moved as yet, we are still waiting for his approval. And his plan.” (Ava)

Even with funding, it was difficult to source housing that met the needs and preferences of the person with HD in the long-term as there was a need for robust housing (due to the movement and behavioural symptoms of HD) and high physical support housing for the latter stages of the disease. On reviewing the qualitative themes with the HD consumer reference group, 1 participant said, “we are essentially getting them out of aged care only to have to go back there again when their disease progresses”.

Where there was success in accessing the requisite funding for disability housing and support, participants described availability of better staff ratios, more choice and control and increased independence for the person with HD. It was widely reported that staff training and expertise was crucial, as the housing and support arrangements tended not to be developed with a specific focus on HD.

One participant described a shared living arrangement in the community that was close to family. As the person with HD’s needs changed, the housing provider made modifications to meet his needs:

“[The landlord] organised in his shower all the things he needed for the shower like a special shower thing that could be moved up and down so the carers could wash him. And the handrails and all that sort of stuff with the toilet.” (Chloe)

“They’ve got a garage that they’ve made into, like, an office. But now we’re going to make that into [person]’s room. He’s got a Huntington’s bed...He smashed it to pieces a couple of times and we just – yesterday we just rebuilt most of it...And then there’s another door being put in where a single door is and they’re going to make that into two doors so he can move in. And hopefully even an inflatable bath, so he can have a bath now. Because he hasn’t had one of those for three years.” (Chloe)

One care giver was offered housing that would help the person with HD move out of hospital. The housing was inappropriate and was in need of modifications. Despite promises to have necessary modifications made within 2 weeks, the housing provider required NDIA approval which was not received in a timely manner:

“NDIS wouldn’t pay for it because it was a rental, and then it - then they had to get documentation to say that they were keeping it as a long-term rental, and then, you know, there’s all this back and forth and weeks and weeks were going by, months and months...” (Layla)

With the housing provider waiting, and the person with HD continuing to struggle, the family member had to step in:

“I ended up taking off the door myself, I removed the door to the ensuite because he couldn’t move his walker, he - there wasn’t enough room to turn his walker around.” (Layla)

After this initial experience, navigating debates between the housing provider and NDIA, this caregiver described how accommodating [the new housing provider] had been in subsequent housing for the person with HD:

“...they knocked out walls, they made two bedrooms into one. They’ve completely modified the bathroom and they’ve even got – like they’ve got the fore – thinking ahead, they’ve gone and put structure in the ceiling so that if down the track [person with HD] should need to be hoisted - they’ve already got that, the beams and structure up in the [ceiling] – the ensuite, they made it – it’s huge, you know...It’s so good and safe and user-friendly.” (Layla)

In addition, the landlord modified internal doors, levelled the entry to the patio to ensure it is accessible for wheelchairs to enter the garden area, they installed rails for movement and adapted the garage to facilitate access.

One person with HD lived in supported housing for 20 months until a fall resulted in hospitalisation.

“...then it was deemed that she required 24-hour care. And so she ended up being in hospital for three months. Then we had the horrible experience of finding out that once you’re 65... if you enter aged care after 65...your NDIS package is then relinquished. So that was just a horrible period because I thought, great, she’s got the NDIS that’s going to be okay. She’s got the supports for life now type of thing. And I thought, I think we thought that she would end up in aged care, but with additional supports, you know, it would be okay...so if you go in as a younger person, you still keep your NDIS package...So I mean I visualised someone maybe giving a massage, taking her out for community access, you know just engaging with her. So that was devastating news. We did a lot of serious lobbying and advocating and in the end, we realised she just would not survive in aged care. So the NDIS have supported her into a [group home] placement.” (Grace)

The importance of the right design of housing and the ability to remain connected to existing communities was emphasised by some participants. Grace reported receiving permission from the NDIA to use existing plan funds to fund 24-hour care as an interim measure as the person with HD’s needs had changed. This allowed the family to apply for disability housing funding which was granted at “high physical needs” level. There was no high physical needs housing available in the regional town that they lived in, so the person with HD moved into a new apartment as an interim option within their existing community. With the accumulation of equipment and the requirement for larger living spaces, bathrooms and doorways, a larger, purpose-built house supporting high physical needs needed to be built.

Although a larger SDA was assured, one of the concerns about the new housing was that it was located in a new community.

“What she’s about to go into is more ideal because she loves a garden, loves a house, but it’s still not where she lived for 20 odd years. So it’s still not really her community.” (Grace)

“...you know these are things that are important for everybody. It's not Huntington's specific. You know, looking at models for group homes and things like that, moving people out of their areas and things, they know, it takes longer to adjust and re-establish themselves...and I guess you know [person with HD] isn't at all independent, she relies on other people...It's harder for her... to make links to new communities. I mean her world is sort of getting smaller I guess. But so long as she's going to have this garden, I think that will be wonderful.” (Grace)

Emma was hopeful that despite the lack of disability housing stock currently available, future housing would be built to ensure people with HD could remain located close to families or in communities where they currently reside.

“So you really hope that in five... years time... that there are options for them... there are properties all around for them to be able to go into... and that they are not stuck in hospitals waiting to find a suitable place for them or that they are not sent [further away]...” (Emma)

Proximity to family and current community was important to participants as was the need for housing to offer access to ordinary activities and outdoor spaces. Emma was optimistic that the new housing she had arranged for her mother would fulfil these expectations:

“So I feel pretty confident you know that this model of care will be more suitable for mum ... not only that but you know they go out on excursions all the time...and the place is really bright and airy ... and there's a kitchen where mum can go and join in with cooking you know mum loves watching the cooking channel or go out to the herb garden ... there's just so many things here that almost give her a sense of normality that she can't get just sitting in her room in the nursing home everyday ... all day.” (Emma)

Experience with the NDIS and funded supports

Participants described a sense of hope that the NDIS would provide housing and supports for the person with HD to experience as high a quality of life as possible outside of RAC. In reality, people described the NDIS as being not fit for purpose for people with a complex neurodegenerative disease with support needs that can change quickly requiring adjustments to funding and support arrangements. Participants described challenging processes around accessing the NDIS and planning, often not knowing what to ask for and a sense that their NDIS planner did not have an understanding of HD.

*“And we went to the NDIS to try and get more care and the problem with the NDIS is, every time you go, you meet somebody different who doesn’t know anything about Huntington’s and you’ve got to go through all the s*** to try and get them to understand what it’s like. And that’s difficult.” (Chloe)*

Some participants reported that the goals of the NDIS personnel differed substantially from the needs and preferences of the individual with HD.

*“They imagine that there’s a lovely little story that [person with HD] would like to go out in the community and go shopping and do this and do that, and I just said to them ‘[He] would like to be able to have his pads changed when he’s s*** himself, rather than sitting in his s*** for 10 hours at night because there aren’t enough staff to change him. He’d like to get that done within a reasonable time. He’d much rather that than wiping his faeces all over his face and all over his bed, which means it takes hours and hours.’ And the woman looked at me and she went, ‘S***’. Because it wasn’t the fairy tale.” (Chloe)*

The main supports received were support coordination, support workers, equipment, home modifications, domestic assistance and allied health (e.g., occupational therapy, psychology and Positive Behaviour Support). The role of support coordination was integral to managing the implementation of these supports, particularly accessing appropriate housing, but the reality of receiving this coordination did not match with hopes and expectations:

“I mean I’ve got a support coordinator now but the one we had previously, he had no idea what he was doing and told me that he had everything ready for [housing] and [disability support] and I was waiting all year saying ‘have any properties come up?’ And he was going ‘oh we are still waiting, we are still waiting’, only to find out that he had never actually lodged any of the paperwork.” (Emma)

This was also problematic when support coordinators remained geographically distant, if their large caseloads slowed down timely adjustments requested by family members, or when there was a breakdown between the person with HD and available support workers.

One participant who had multiple family members utilising NDIS highlighted the discrepancies between plan implementation based on geographical location. The participant's sister was able to:

"[G]o out and she does craft, she goes out, she goes to bingo, she goes out to, you know, 10 pin bowling or something...She goes on holidays, you know" whereas another family member was unable to make use of his plan due, in part, to lack of available services and opportunities: "He has his plan, he has his plan that's not being used and can't be utilised." (Isabella)

Some caregivers reported paying more if they accepted housing located a distance from services:

"So his physio and the speech therapist and all those people that were involved in his care - it was costing us more money because they would have put an extra half an hour travel time to and from." (Layla)

Given the cognitive sequelae of HD, it was important that service providers be proactive in maintaining engagement:

"See, at one stage when his plan first came into – into provision, I was able to get in touch with – and I did a lot of this work myself - getting in touch with physiotherapists, speech therapists, and occupational therapists, and some of them did travel to [location] and they had appointments with [person with HD]. But that just all fell by the wayside, you know, and then maybe he didn't turn up for one appointment because he does forget things and - he loses his phone and doesn't even know what day of the week it is. So yeah, it was at one stage being utilised a little bit with some of the services, but now it's just, like, dead, nothing's happening with his plan." (Isabella)

Engagement was further limited when support relationships breakdown:

"...he's had supports... but he argues with them and has – because of his – his cognitive angers and things - the problem with the brain - he is aggressive, he argues, and I don't think he's got any household supports at the moment." (Isabella)

One participant discussed the NDIS funding associated with a degenerative condition such as HD whereby capacity building funds are reduced over time due to the impossibility of functional improvement with therapies:

"...unfortunately, with things like Huntington's things like physio ... which she was able to access in the first year and have regular physio sessions ... because they see Huntington's as a progressive disease with no kind of um: they can't improve ... they then the following year every year you know the amount that they give for physio does decrease because they think well really she's not going to end up walking." (Emma)

A reduction in NDIS funding was also experienced by Layla whereby the NDIA “cut everything” in the yearly plan review. The support coordinator, behavioural therapist and occupational therapist are reportedly compiling:

“quite intense reports, well documented, but they’re putting extra stuff in...and then our OT is doing a step by step of – of a daily routine to try and show how much support he needs now. Because he’s – he - he has declined quite quickly. You can say over each three months, you could say there’s a big drop in his ability to be able to do stuff...”
(Layla)

The NDIS funding changes have not accounted for the rapid changes in the person with HD’s condition. In addition, the person with HD is awake at night requiring additional hours of care to be added into the original plan.

Notwithstanding the above issues with accessing NDIS supports, several participants discussed NDIS funding that was available after their family member with HD was admitted to RAC. The opportunity for time spent outside the facility was one example of how this had improved the quality of life for a person with HD. This also provided family members with the opportunity to meet in a more relaxed environment.

“Where you can see more expressions on him when he’s out in the community and you can see that he’s enjoying the sunshine and you know he’s enjoying the activities and he’s smiling.” **(Ava)**

“I hate, I actually don’t like visiting him there just the environment and you know, I find that, I find it easier if I say to the carer “hey look I’ll meet you at the movies or at the park.” **(Ava)**

William expressed gratitude for the NDIS funded support received to lighten some of the household duties the family were otherwise responsible for. They were optimistic about the direction of the NDIS and how they could increase the support needed as HD progressed. While they did not have personal experience regarding the next steps with NDIS support, they did note:

“we’ve spoken to a few people, especially those who have kind of got onto NDIS and managed to shift, you know, their family member from aged care into another setting that it’s just been really like, life changing for them as well. So, I – yeah, I’m hoping that, you know, NDIS will open up those opportunities so that that’s not the – the option that people have to go to.” **(William)**

Key elements of housing and support requirements for people with HD

Participants described a number of key elements that they considered crucial for housing and supports for people with HD. Accessible housing needs included wide doorways and hallways, large bedrooms with space for furniture and mobility aids (e.g., hoists) and bathrooms with space for showering aids (e.g., shower commode) and support staff. Regarding the environment, participants reflected on the clinical and sterile nature of existing housing options and highlighted a need for places to feel like a home, have plenty of light and access to fresh air and a garden. Location emerged as a key element of housing with a recognition that if a person is housed too far from their existing community, they are at risk of increased isolation and loss of informal supports. This included people in regional areas who opted for a RAC closer to home rather than moving into a metropolitan area for HD specific housing, and people in metropolitan areas who stated that if housing is too far in the suburbs, there is less likelihood of people visiting. Ultimately, participants expressed that as well as the practical needs, the environment needs to be an inviting place for family and friends to visit and stay over if desired.

"I think open space is a big thing. Like, clear open rooms with lots of light. I really believe that. Like, he has the lights off some days and you can tell when he needs the lights off, but it's still a big room." **(Chloe)**

Purpose-built facilities for people with HD were considered essential by some participants. There would be great benefit in having "a Huntington's-registered facility with trained staff that actually have a background in understanding and knowing of Huntington's" (Sophia). This participant then described a model, based on a previous model (non-HD) they had encountered that they believed would work well for people with HD:

"...two, four, six – eight houses, two houses on each site and each house is run by staff 24/7. And the houses interlink to one another so you've got four residents per house and then you just have two staff members that run that house 24/7... so you would have a morning service from 8 'til 2:00, from 2:00 'til 8:00 at night or 10:00 at night, from 10 'til 6am. You'd only have an overnight if you had risks like fall risks or ones that had issues or problems during the night and then it would be active service so the carer would be awake the whole shift instead of a sleepover." **(Sophia)**

The need for HD trained staff and improved ratios were interlinked.

"I mean I'm not putting nursing homes down, but I mean we see in the media all the time that they're understaffed. But also, whether the staff would be trained. We've not had any support staff that have had experience with working with people with Huntington's diseases, but everyone has gone above and beyond to find out what they can and do the best they can. So we've been really really lucky. Yeah, in that support, so we're grateful for that. Extremely grateful." **(Grace)**

A significant problem experienced by a family member with HD was being placed in housing that was geographically distant from family members and suitable supports. The only support service was described as “run off their feet” (Isabella). With the support coordinator living up to 3 hours away and a lack of trained supports in the location, the family member suggested an education program, even if this was to be conducted using online platforms such as Zoom.

The potential for greater education and training and the valued support already provided by staff and services associated with HDAs were raised by several participants. One participant was able to arrange for HDAs to train all the staff who were support workers in a shared house (Ava). Another participant, Chloe, provided information to support workers about training by HDAs, and, as an interim measure, Chloe provided them with informal training based on their personal experience as a carer. Uptake of training was also raised by Emma who noted,

“... you can have somebody from [HDAs] go out ... and try and upskill the staff but it's where they go after the training whether they implement those strategies... so many times... we've had mum's behavioural therapist go in or [HDAs] has come in with some ideas or something like that but then it's just not implemented beyond... that training session. I guess because there are time restraints, or they can't provide 1:1 care all the time because ratios are you know 1:20 or whatever it is I don't know their exact ratios in nursing homes but... it's just such a high turnover of staff which is what you do notice that information doesn't always get passed on.” (Emma)

One particular model, where specialist-trained staff supported people with HD (and/or similar neurodegenerative conditions) in a small share-house design, was discussed by 2 participants:

“Yeah so there's three, three other gentlemen in the house and then he has a one on one five hours every day so they make a plan on what they want to do. So they've got a little hiatus they might make a plan where everyone goes out and they do the same activity.” (Ava)

“...they've got the group homes in the community but then they've also got day programs. So majority of the clients that actually live in the accommodation houses go out to day programs where they all join up together. So it might be five houses meet up at the [location] site and they do activities all day or go bowling together and then they're interacting with other people, it's not just their four housemates. So it's more like a big communal family thing.” (Sophia)

Advantages of this housing model were described as facilitating social interactions, allowing people to participate in community engagement activities, and have family members visit while having accessible continuous care. In addition to the inclusiveness described, Sophia also discussed the importance of incorporating dual purpose respite when designing housing:

“It doesn't have to be the group homes; it can be a respite facility built like the group homes but then that can accommodate some of the care workers – the carers that actually need that rest or that are struggling...” (Sophia)

Aspirational considerations for the future of HD specific housing included the provision to allow family members to stay:

“...for my housing in the future I would like to be in a facility like a [organisation] accommodation where my family can come visit but don’t have the burden of having to look after me. We chose to look after my parents but that’s an option that I would give my children, or they would have but I wouldn’t expect it. So I would like to know that yes, that if they don’t want to or they choose not to, I am comfortable with going into a facility because I believe in that facility, I have positive connections with it, I’ve seen how it works, I’ve watched it develop, watched it grow so you’ll feel safer going there...”
(Sophia)

“...[one place I know of], there’s a cluster of villas or small residents and then like one apartment or one unit where the staff are. For people with [the early] stage of Huntington’s, that could be a good thing? You know where they’ve still got their independence, and depending on the requirements of the individuals, they’ll get the support they need. They know that there’s someone just across the courtyard or just down the driveway a little bit, 24/7... they can get that care.”
(Grace)

The role of advocacy

Many participants described the advocacy role they have played in the lives of their close other/s with HD. This included advocacy in the medical system, hospitals, navigating the pathways in and out of RAC and accessing NDIS funding and supports. Several participants attributed the presence, quality and quantity of their close other’s funding and supports to their own advocacy. Rather than a discrete action that can be ceased once an individual secures funding, housing and supports, the role of advocacy was described as being ongoing:

“I do follow things up and look, I am constantly in contact with therapists ... if you don’t ... If you don’t do that... it will be months before ... someone goes out to see her or you know you don’t get any updates on what’s happening I am constantly on the phone to the therapist or the coordinator or the nursing home.”
(Emma)

“Yeah I am involved. Yeah it’s funny how life works out, but I do work in the disability sector... so that’s served me well I guess. So it sort of works both ways, sometimes my personal experience can feed into my work... in a professional way. Just being exposed to different situations and scenarios, and then vice versa. But I think you know, even if someone is – the advocating never stops.”
(Grace)

When discussing the process of completing NDIS forms, Mia noted, “I’ve got two university degrees and I struggled with the process” and stated concern that “if I hadn’t of done it for [person with HD] ... she’d be on the street right now....And so what I would suggest is there needs to be people whose job it is just to help them fill out the forms....that – just to help do the actual paperwork. It’s so difficult.”

Understanding the language used when completing NDIS forms was another barrier.

“...when [person with HD was] first was accepted under the NDIS I had actually said I need a support coordinator because all the language was alien to me then.” (Layla)

One participant described the alarming outcomes for people with HD who have no informal supports to act as advocates:

“...people with Huntington’s that don’t have a family member that can speak out for them, they do get stuck out in a nursing home...there’s three residents there that have been in the hospital for nearly a year now because they can’t find suitable housing or they don’t have anyone to advocate for them ... to find suitable housing...” (Emma)

Education and advocacy organisations, including HDAs, were praised by Olivia for providing guidance in relation to processes and practical steps, for example when symptoms worsen they provide advice on sourcing proactive housing solutions. There are also in-person and online support groups for carers. HDAs were recommended by multiple participants for helping caregivers connect with necessary supports. For example, a connection with HDAs led to a visit from a social worker which ultimately led to visits to a Huntington’s clinic providing access to “neurologists, speech and all that sort of stuff” (William). These services were then provided closer to the participant’s home and the local community health centre provided assistance in applying for NDIS.

In seeking advice on how to help a person with HD transition into new housing, Grace sought advice from HDAs. They were able to discuss the feasibility and benefits of moving into new housing, reassuring the caregiver that rather than seeing it as disruptive, a move would provide the person with HD with something to look forward to and adapt to.

“And she is really excited...her workers take her every week to see the progress. They send through photos, so yeah, sounding positive already.” (Grace)

HDAs also have greater insights into what living configurations have worked for people with HD; some “living in [NDIS funded] properties by themselves” ...others with “3 or 4 people” and some who may have tried living with housemates but it did not work (Grace). HDAs also checked in with people and reviewed their ongoing needs:

“We would have the Huntington’s team come out every six months and see Dad and review and just check in to make sure everything was okay and if there was anything that we needed.” (Sophia)

Despite the presence of advocacy groups, and the significant role of HDAs, family member’s information needs were generally unmet.

“It was just it would have been a bit better if we had that more background information and more understanding of Huntington’s. We’ve only been told ‘oh hey, your dad’s got HD’. Within a couple of years he was gone from walking around being a [tradesperson] that went to work seven days a week, to having a fall at home, to having a frontal lobe head injury, to coming out of hospital with Huntington’s disease so it was all like a big shock. We were still getting our head around it during the whole process of his care and [the] majority of my family still don’t understand and know Huntington’s well...I’ve even got family members – my uncle passed away, was in denial. Didn’t want to have testing because of watching my dad and everything else.” (Sophia)

The supports needed for a family can be associated with how to cope with the diagnosis, the high probability of passing on the gene, the age to educate children about the gene, and support to decide if/when to get tested. Sophia knew that she was gene positive and was concerned about the future health of her children:

“it’s like well you’ve given your kids a death sentence”. Another reflected on the perspective of the child witnessing the decline in health of a person with HD and the potential of being gene positive themselves, “they’re looking down straight into their future. So it’s a horrible thing.” (Grace)

However, being tested and having knowledge of being a genetic carrier was also seen as a positive:

“The more I know, the more I can prepare myself, train myself, find out things, get research done. So by the time that it does affect me, I can say ‘well, look, there’s this in place, there’s these places here, I know to reach out to this certain area or these people for assistance and help’. But living in the dark or the lurch, that would be more of a – yeah, so I was like – no, very keen to get my testing done but some of my family members were standoffish.” (Sophia)

In discussing how information needs could be better accommodated, participants discussed the need for regular and manageable information that can be provided upon initial diagnosis, subsequent gene testing of other family members, and follow up information to meet the changing information needs as they progress.

“...it just seems like a big information overload and there’s not enough little clippets [sic] out there to fully explain and target X, Y and Z of HD.” (Sophia)

Discussion

It is evident from the qualitative interviews that people with HD remain a population with a lack of viable choices outside of RAC when it comes to housing and supports. The experiences of those who enter RAC are characterised by loneliness, isolation, functional decline and even injury. This finding aligns with the growing literature highlighting the detrimental impact of younger people (i.e., aged 18-65) living in RAC (Oliver et al., 2020). Indeed, the Younger People in Residential Aged Care (YPIRAC) strategy in Australia asserts that there should be no new admissions of people under 65 into Residential Aged Care by 2022 and no young people in RAC by 2025 (DSS, 2020).

Despite this, people with HD have very limited options regarding where they live, how they live, and who they live with. Participants attributed this to a number of factors including lack of geographically appropriate housing that is disability accessible and physically robust, lengthy delays in funding decisions and inadequate funding for housing and supports, insufficient education and support for family caregivers, and insufficient HD-specific expertise among NDIS planners, support coordinators and health and disability support staff. These gaps are costly for people with HD and their close others in terms of the impact on social, occupational and psychological wellbeing and costly to our health and disability systems as people with HD experience lengthy hospitalisations and/or require emergency respite housing whilst permanent solutions are debated for many months.

Changes to the NDIS and housing sectors to provide housing and supports that align with the needs and preferences of people with HD will be mutually beneficial from financial and psychological perspectives. Investment in supporting people with HD to stay at home, where viable, may delay the need for expensive housing and support models for a number of years. When people do require full time care that cannot be provided in the home, investment in housing that is robust, physically accessible and close to an individual's community has the potential to reduce ongoing support costs due to the presence of assistive technology and availability of informal supports. Investment in allied health and Positive Behaviour Support services to provide assessment, training and implementation for formal and informal caregivers may enhance quality of life for people with HD, reduce caregiver burnout and staff turnover and, hence, be more cost effective in the long term than current reactive models.

Needs according to living situation

For those supporting individual/s with HD to remain living at home, there were often unmet needs in availability of suitably qualified health and disability support. There were instances where home modifications were necessary and this fell to the informal supports to cover the costs. Participants reported feeling ill equipped to manage behaviours of concern and other psychiatric symptoms of HD, sometimes leading to a breakdown in family dynamics and living arrangements that were not sustainable. Where people had access to disability supports and/or respite, these were regarded as helpful and made remaining at home more sustainable. Provision of expert disability and allied health staff (including Positive Behaviour Support clinicians) early on and throughout the trajectory of supporting somebody with HD represents an opportunity to allow people to remain living at home for longer if that is their preference.

Participants described a variety of potential supported living solutions including single dwellings and shared support models. It was evident that RAC was not a viable solution for younger people with HD due to the psychosocial impact of living with people much older than them, largely poor care, risk of injury and assault and isolation.

Common key elements of preferred housing and support models included being geographically close to existing friends and family, disability accessible (i.e., wide doorways, bathrooms that can accommodate equipment, accessible entry etc); robust fit out due to behaviours of concern and uncontrolled movements that can damage property; space for family members to stay; a homely environment that people want to visit and access to light, air and garden. Some participants described potential shared housing and support models with an emphasis on the individual having their own self-contained space with shared supports.

Housing options need to be a viable solution for the individual throughout the course of their disease so that they do not need to return to RAC or hospital as their disease progresses. Where shared models were discussed, particular attention needs to be paid to the cohabitation of people at various stages of the disease. Preferred models included those that applied a stepped approach, whereby people move from a lower care part of the facility to a higher care section when the individual is no longer able to interact with their environment and requires high physical care.

NDIS funding and supports

There was consensus amongst participants that although the NDIS provided much needed disability funding, it was not fit for purpose for people with HD. Funding decisions for housing and supports needed to live outside of hospital or RAC were lengthy and required a great deal of advocacy from informal supports. Even once decisions were made, the funding was often inadequate for people to have their reasonable and necessary needs (i.e., supports needed to live safely and with dignity) met. When needs changed quickly (e.g., due to disease progression and/or breakdown in the informal caregiving arrangement), the NDIS was not responsive enough to provide funds to mitigate risk of extended hospitalisation or admission to RAC. The NDIS personnel and disability sector staff (i.e., support coordinators and support workers) often did not have an adequate understanding of the unique nature of HD as a disability that can change quickly and encompasses physical, psychiatric and behavioural needs. Family members often took on the role of educating these professionals, who typically turn over regularly, adding to the caregiver burden and delays in adequate care being provided. Participants highlighted a need for somebody, whether within the NDIS or in the disability workforce (e.g., support coordinator), who has the requisite knowledge, skills and time to support the navigation of NDIS, housing, health and/or RAC sectors.

Implications

Given the various unmet needs expressed by the participants, it is evident that the solution to the housing issues faced by people with HD is multifactorial. This requires innovative changes to housing developments and availability (i.e., bricks and mortar) and/or repurposing existing housing. There is a need for a workforce that is funded, trained and supported to deliver required health and disability supports for people with HD to live safely and with dignity outside of hospital and RAC facilities. There is a need for funding for housing and supports to be flexible so that support needs that emerge quickly can be met, and responsive so that major changes to housing and support needs can be actioned efficiently and effectively. Finally, there needs to be expert coordination available to support people with HD to navigate the complexities of disability and housing support sectors. Such investments are crucial for caregivers to remain able to provide informal supports, and for those without informal caregivers to receive equity in the provision of housing and support solutions.

The housing and support needs and preferences of people with HD are complex, dynamic and can change with little warning. Early in the disease and/or when the person with HD is living at home supported by family, there is a need for expert health and disability supports to ensure that this arrangement remains sustainable. This includes allied health, Positive Behaviour Support, education and psychological therapies for caregivers. Allied Health and Positive Behaviour Support clinicians should also provide training, mentoring, supervision and support to those providing disability support to increase their capacity and reduce burnout and subsequent turnover. For this to occur, NDIS plans will need to be funded accordingly so that disability support workers can attend mentoring sessions in a paid capacity. Importantly, these supportive interventions are not a one-off “set and forget” model; rather, clinicians need to be resourced to provide ongoing mentoring to adapt to rapidly changing needs and upskill new employees as the workforce inevitably undergoes turnover.

There is a need for housing that can support individuals throughout the trajectory of their disease (i.e., a combination of robust and high physical needs housing). Currently, there is a risk that as an individual's disease progresses, they will return to RAC or be hospitalised indefinitely. Housing stock should be available to people in locations that are close to existing communities irrespective of their metropolitan, regional or rural status. Regardless of the living arrangement, the built design of supported HD housing should encompass a home-like non-clinical environment, inclusive of outdoor space and access to gardens if preferred, with spaces for friends and family to comfortably spend time. Such considerations may encourage more friends and family to visit and should be considered reasonable and necessary to support the individual with HD to live an ordinary life.

Where communal housing models exist, there should be consideration of the impact that living with others with more advanced disease can have. This may include models where individuals progress through different stages of care within the same property as their care needs change. Such a transition may provide minimal disruption for individuals and families as their disease progresses as they remain within the same property, ensure their physical support needs can be met adequately at the advanced stage of the disease and allow people in the early to middle stages of the disease to reside in closer proximity together. Irrespective of the communal housing model, individuals should have sufficient space (i.e., their own bedroom, bathroom, kitchen and living area) so that they can spend time alone (or with family and friends) away from other residents if they prefer. Communal social settings, including gardens, facilitate opportunities for interaction and socialisation. Similar to those being supported at home, availability of disability support workers (and nursing staff if required) who are trained, supervised and mentored by allied health and Positive Behaviour Support professionals is a crucial component of a skilled and consistent workforce.

Disability and health supports should have expertise in the unique symptom profile of HD and match their support provision accordingly. This includes training in Positive Behaviour Support, motivational strategies and provision of care that meets the individual's needs whilst continuing to encourage independence.

The NDIS should provide a funding model that adequately reflects the housing needs and preferences of people with HD with flexibility to direct funds where they are needed when the person's needs change unexpectedly. Given the unique complexities associated with HD, it may be necessary to dedicate specifically trained NDIS planners to ensure that NDIS plan development and implementation are done in an effective and efficient way.

A greater need to support close others was identified with specific references to carer burnout, counselling to accompany diagnosis, increasing respite options, and ongoing education and psychological support. Regular and manageable information could be provided upon initial diagnosis, subsequent gene testing of other family members, and follow up information to meet the changing information needs as the disease progresses. Information needs extend to the challenges that accompany the NDIS.

As informal advocates, close others require greater guidance on how to navigate the complex systems, and access increased supports and timely specialist advice and assistance as the disease progresses. In the absence of adequately skilled support coordinators or dedicated planners with HD expertise that can spend the time needed to coordinate the complex interfaces between disability, housing, hospital and RAC sectors, it may be useful to engage specialist services to meet this need.

People with HD have unique physical, cognitive and behavioural support needs that mean they require housing and supports that are fit for purpose. Therefore, funding needs to be flexible across core, capital and capacity building budgets so that things like equipment, extra core supports, Positive Behaviour Support, respite and minor home modifications can be implemented quickly so that injuries, caregiver burnout and extended hospitalisations can be avoided. For more major changes to plans, there should be an efficient pathway for this to happen quickly (e.g., for major home modifications or SDA determinations).

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