



Improving treatment and care through representation, advocacy, education and research

HFA GETTING OLDER PROJECT

Community voices

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Needs Assessment

Background and aims

With larger number of people with bleeding disorders living into their senior years for the first time in Australia, the project aims to:

- identify, understand and respond to the range of needs people with bleeding disorders may have as they grow older

and

- help find appropriate solutions for them and their partner/family or friends/carers.

Needs Assessment

Consultations held to date

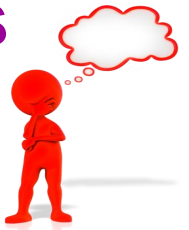
- Interviews with community and health professionals: 40
- Community forums held: 2

Targeted age group – getting older?

- Need to take into account early ageing issues.

Community voices from needs assessment

This presentation offers a series of quotes around the lived experiences of the persons affected with a bleeding disorder.



- The needs assessment consultation involved interviewing the bleeding disorders community members seeking to understand their needs around getting older.
- Themes taken into considerations for this presentation includes, hopes and aspirations, concerns and uncertainties and needs around getting older.

Community voices : Hopes and Aspirations

- ‘To lead a worthwhile, active and fulfilling life as possible.’
- ‘I am hoping to have a treatment and a cure for haemophilia’.
- ‘In general, I hope for things like financial security. Being able work long into older age. Staggered hours.’
- ‘Enjoyment of my grandchildren. The relationships that I do have with people. They will be comforting and reassuring in my lucky years.’



Community voices : Hopes and Aspirations

- ‘It is important to think how will I live in my old age, how will I have supports around me and the social networks and family around me.’
- ‘Have little less discomfort and pain than I am currently going through.’
- ‘I hope to have more time for myself in particular to read and as an artist.’
- ‘What I hope to be able to do is retire - scale down from full time work in about 10 years, when I turn 60. I am hoping that my orthopaedic needs are addressed.’

Community voices : Concerns/Uncertainties

- ‘There is always a pain coming from somewhere related to past traumas from bleeds... whether I have fallen over or something.’
- ‘The things that affect me the most are joint stiffness and pain, fatigue, vertigo, depression and side effects of medications.’
- ‘It has been difficult to see my issues as a part of the ageing process or something there for most of my life *as it (my haemophilia arthropathy) has been there all my life.*’

Community voices : Concerns/Uncertainties

- ‘I think the biggest challenge I might face with treatment is if I ever ended up in aged care facility and have incidents where I fell out of bed.’
- ‘Finding courage to use different locations to access veins’.
- ‘Each time going to different locations for accessing a vein is like starting over psychologically.’

Community voices : Concerns/Uncertainties

- ‘I am not strong emotionally.’
- ‘I live on a day to day basis. I don’t have a plan for when I get older.’
- ‘At work I have direction, but outside work I have no direction.’



Community voices : Concerns/Uncertainties

- ‘Facing some financial, some physical, some mental challenges at the moment.’
- ‘The thought of me losing my independence is not something that I look forward to.’
- ‘I am concerned that she (my wife) will take the brunt of the caring.’



Community voices: Needs around getting older

- ‘Continue my physical independence, even with slow decline of my health.’
- ‘This may involve improving my health to be worthwhile in society.’
- ‘Because I have got damaged elbows, (this is going to sound ridiculous), just personal care when I go to the toilet is becoming hard. My elbow is very stiff.’



Community voices: Needs around getting older

- ‘My stiff elbows mean I am having more trouble doing shaving, doing my teeth, doing my buttons, wearing a tie. Each of these problems require unique solutions such as long-handled toothbrush, dressing more casually...’
- ‘I worry that as get older, my lack of dexterity in my hands, elbows, legs, onset of dementia, or being in residential care, may affect my prophylactic treatment...If I can’t do it somebody else has to do it.’

Next steps in consultation

- National community survey
- Developing practical online solutions
 - Community focus group

Other data

- Collating age-related data from Patient Reported Outcomes of Burdens and Experiences Study (PROBE).

Project outcomes:

- Needs Assessment Report
- Online platform on HFA website



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