

CURRENT EXPERIENCE



Fatigue

Shortness of breath
LIMB WEAKNESS
Light-headedness

Most common symptoms observed before diagnosis

6 tests

DIAGNOSIS CONFIRMED by 6 TESTS ON AVERAGE

47%

FELT SUPPORTED AT DIAGNOSIS

13%

FELT THEY HAD SOME SUPPORT AT DIAGNOSIS, BUT NOT ENOUGH

75%

Knew LITTLE or NOTHING at diagnosis

Diagnosis & prognosis



53% reported a negative impact on QoL

Quality of life

47% of participants had a preference for talking to someone



86%

FELT RESPECTFULLY TREATED THROUGHOUT THEIR EXPERIENCE

The main source of information came via THE INTERNET



Communication & Information

General practitioner
100%

Cardiologist
96%

Haematologist
93%

17%

Felt they were not really provided with treatment options & only one treatment discussed

Access to health professionals

Conversations about treatment

PERSONAL

EXPERIENCE

EXPECTATIONS

KNOWLEDGE

PEEK

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CARDIAC AMYLOIDOSIS + OTHER FORMS OF AMYLOIDOSIS

AUSTRALIAN STUDY 2020



CENTRE FOR COMMUNITY-DRIVEN RESEARCH

Research, they need the money for research, I guess, because that's the way they're going to be able to help a lot more people.

I'd suggest that it may be a little bit more for some Australian research would be appreciated. The health system itself, well, as I say, I think is the best in the world. I've looked at the health systems in a few countries around the world.

I would say that medication that has been shown to be efficacious overseas, and there's plenty of data for that, that medication should be put on the PBS as soon as possible...That should be covered by PBS and that makes it affordable for everybody

I reckon there's a lot more people that are affected by this than they have any idea about. I think genuinely there's probably a lot more people suffering from it than they've ever heard about what it is. It's a bigger issue than people realize

messages to decision-makers



Treatment

Treatments need to be more affordable and more effective



Care & Support

Better access to support services



Information

Needs to be easier to understand



Health Professional Communication

Health professionals need a better knowledge of condition

future expectations

CCDR would like to thank each and every participant in this study