

How to manage your heart failure in amyloidosis

Cardiac amyloidosis is a condition where abnormal proteins called amyloid fibrils build up in the heart tissue. These proteins make the heart stiff and less effective at pumping blood, which can cause heart failure. Heart failure in amyloidosis is a long-term (chronic) condition which needs lifelong management.

Managing heart failure has many parts. You may need to adjust your daily life to help you feel better. Taking an active role in managing your heart failure will help you stay out of hospital and live a better, longer life. Use this plan to identify the parts of your heart failure management that you can focus on. Remember that these may change over time. Your personalised plan may include any of the following actions:



KNOW:

- The signs of heart failure worsening and who to contact for help (GP, heart doctor)
- When to see your health professional
- When to update your action plan

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MONITOR:

- Your daily weight (same time each day!)
- Your daily fluid intake, don't forget fluid in foods like soup, fruit and ice cream
- Limit salt intake (<5 gram per day)
- · Minimise alcohol intake
- Stop smoking



MOVE:

- Aim for 30 minutes of moderate intensity exercise daily i.e. fast walking
- Join a cardiac rehab program or discuss an exercise plan with your doctor
- If you feel very breathless, dizzy or have chest pain seek medical attention



TAKE YOUR MEDICATIONS:

- As prescribed by your doctor, even if you feel well – prevention is key!
- Consider medication aids (i.e. medicine packs, reminder applications)



CONNECT with:

- · Family or friends regularly
- Support groups for people with amyloidosis or heart failure
- Mental health support services if needed



For more information:

- 1. Visit our website via the QR code
- 2. Visit the Amyloidosis Network website: https://aan.org.au



Managing my amyloidosis heart failure: my plan

Name:	Date:	Review date:
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Take medication as prescribed

I take my medications as prescribed by my doctor, and I keep a medication list with all the medicines that I need to take for my heart failure and other conditions with me on my phone or in my wallet.



Get active

Every day I should aim to do **30 minutes of moderate intensity exercise**, such as walking. Include balance and flexibility exercise on most days and strength exercises on 2-3 days per week.



Monitor

I monitor my weight, fluid and salt intake to prevent the buildup of extra fluid in my body.

My healthy weight is:	I can have up to:	I can have up to 2000mg of
kg	litres	sodium per day. This is
	of fluid per day.	about a teaspoon of salt.



Know

I need to call my GP within 24 hours if:

- ✓ I gain or lose 2 kilograms over 2 days.
- ✓ I have worsening shortness of breath with my normal activities.
- ✓ There is increased swelling in my ankles, legs or abdomen (my shoes, socks or pants are getting tight).
- ✓ I am coughing a lot especially at night.
- ✓ My heart is beating very quickly.
- √ I feel very dizzy or pass out (faint)
- ✓ I am generally feeling more tired or sad than usual.



Connect

I can seek extra support and connect with:

- ✓ Family or friends
- ✓ My GP or cardiologist
- ✓ My local heart failure/cardiac rehabilitation service
- ✓ Australian Amyloidosis Network Patient Support Group

If you are unwell or require urgent medical care, please contact your GP or present to your nearest Emergency Department