

## strive Carer Support Group

Topic Sheet – August 2022

Advocating for your loved one

When your loved one is diagnosed with an eating disorder it can feel like you've landed on another planet. The symptoms and behaviours make no sense, and it can take a while to completely understand the different ways the illness is impacting your loved one. You may feel guilty that you didn't notice the signs and find that your natural way of responding is not making a difference. These are all valid feelings that are completely normal.

Your loved one may not realise or accept there is a problem, or they feel afraid and ashamed to seek help. They may be ambivalent about changing behaviours and in many cases fight hard against anything or anyone trying to help.

It's near impossible to help your loved one alone and one of the most powerful things you can do is to learn how to advocate for them - they need you to be their voice and to find treatment and support that meets both their needs, and the needs of your family. As their greatest advocate you'll feel more empowered and confident over time, and remember, you are saving their life.

Here are some tips for how to do it:

1. Learn as much as you can about your loved one's diagnosis and learn fast! You may never understand why this has happened however you can learn as much as you can to help them recover. Arm yourself with information and resources and share information with others to help in getting the outcomes you need.
2. Prioritise who you need to speak to and **make a plan**. This includes family, friends, GPs, clinicians, schools, sporting clubs etc. Having a clear view of what you're doing and why, is very empowering. It's an ongoing process and you'll need to continually reassess.
3. Do your due diligence in selecting a treatment team and aim to forge strong, trusting relationships. Aim for continuity of care if possible and manage your expectations, however don't be afraid to change if you feel you need to.

Consider making appointments to see clinicians on your own. You can be more open about what is happening, and it also gives you a chance to assess if they have an approach you feel can work for your family.

4. Be prepared for some difficult conversations as myths and stigma around eating disorders are widespread. Expect to have to challenge and educate others, and be ready to repeat yourself over and over.
5. Approach every conversation with a plan based on who it is. What messages do you need to convey and what outcomes do you need? Rehearse what you need to say and take notes to all appointments – there is limited time and so much to say. Emotions can take over and you can miss communicating important information.
6. Trust yourself and trust your gut - you know your loved one best. If something doesn't feel right, trust yourself to speak up. Never doubt the importance of your role and input in the treatment team.
7. Be inquisitive – ask questions and double check if you're not sure about something. Insist on answers if you believe it's something you need to know. There is no such thing as a dumb question!
8. Keep notes as the days, months and years can become a blur – don't assume you'll remember everything. The health system is fragmented and you may have many different people involved over the journey. A daily diary can be a wonderful resource when your brain is struggling to keep on top of it all. Include information about the behaviours and symptoms you observe, appointment outcomes and things you need to follow up. Being able to describe things accurately when needed, can help improve treatment outcomes.
9. Give feedback both positive and negative – if something is working well, tell those involved. If you have concerns, raise them and follow up if necessary.
10. Understand your rights and how they apply to your situation. Australia's healthcare rights are set out in the [Australian Charter of Healthcare Rights](#). These rights apply to any healthcare in Australia, including public hospitals, private hospitals, general practice and in the community. Keep them handy and refer to them if you need to – they are there to empower you.
11. Familiarise yourself with the relevant legislation in your state or territory: Mental Health Act, and Guardianship Act. You may never need it however it's good to have a basic understanding in case you do.

Being an advocate can be emotionally exhausting and overwhelming, however also empowering and rewarding. Focus on what you can control and pat yourself on the back for the small wins along the way.

Everything you do is helping your loved one in their recovery – even if it doesn't always feel like it. Be like a dog with a bone and you'll find strength you didn't know you had!

Some of your biggest supporters are in this group, so utilise the **strive** Australia Facebook Group and support groups to ask questions and share experiences.



## EDFA Member only Resources

Negotiating the pathway for your loved one by Ella Graham (slides from an EDFA Education webinar) <https://bit.ly/3zvDPbL>

## Other helpful resources

Musby, E (2021) *Anorexia and Other Eating Disorders*, Chapter 3.

Practical measures schools take to support pupils with an eating disorder  
<https://bit.ly/3zW4eAY>

Connect ED: finding and connecting with a health professional experienced in eating disorders <https://bit.ly/3PcL5zj>

Create your Advance Care Plan <https://bit.ly/3oTH1cw>

My HealthCare Rights (Consumer version) <https://bit.ly/3JIQQ6J>

CEED's Eating Disorders Care and Recovery Checklist for Carers <https://bit.ly/3JtrDNb>

This topic sheet can be found at [bit.ly/3cU43go](https://bit.ly/3cU43go)



## References

Shared knowledge and generosity of those with lived experience

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