



## Self-advocacy

An important aspect during transition is developing the ability to ask questions and communicate your needs independently, this is called self-advocacy. In most cases, you would have already started to engage with your existing care team without a support person present before transition. Here are some tips to help you on your journey to successful self-advocacy!

Listen to your body and share what is, or isn't working well, early on. It can be tricky at times to manage all your cystic fibrosis care needs, however, it is important you prioritise your health and communicate challenges as they arise. Don't leave it until you are unwell or unable to manage at all to communicate your needs.

*"Your body knows how you are feeling and if you are not coping, with weight, or anything... you know to do something about it"*

*- Adult living with cystic fibrosis.*

**Take action:** Your cystic fibrosis clinical care team is there to help guide and support you in becoming more independent in managing your healthcare needs. Building trust and confidence with your new care team can take time but it requires commitment from both sides. Once you begin to act with your treatment you will feel more in control of your health and gain a better sense of what to ask and what you need from your team.

*"It's more empowering for the person who has cystic fibrosis because, if you feel as though you have agency with your treatment, then you are more likely to stick with it"*

*- Adult living with cystic fibrosis.*

Explore your communication options: If you are living a significant distance from your outreach clinic it is important you have a way to communicate with your cystic fibrosis clinical care team and ask questions outside your regular appointments. Options like email, text message or phone call are generally all available, along with intermittent Telehealth appointments. Discuss your options with your team directly.

*"I think communication is probably one of the signature things that my care team does really well for someone who is not living in Brisbane"*

*- Adult living with cystic fibrosis.*

## Knowledge check!

### I know and understand...

- ☐ Asking questions will help me learn more about my cystic fibrosis.
- ☐ Sharing challenges early on will help me to manage my health.
- ☐ Finding ways to take ownership of my treatment can help me feel empowered.
- ☐ Exploring treatment options that feel right for me is important.
- ☐ Building trust with others takes time and effort on my behalf.
- ☐ Ensuring I have a way to communicate with my cystic fibrosis clinical care team is necessary.
- ☐ Where to go for help if I need further assistance or more information.