



Support network – family, friends, and carers

Transitioning to adult care is a unique and individual experience, just like living with cystic fibrosis, however all young adults will at some point move to adult care and all will need continued support. Some changes during transition can be naturally expected, such as beginning to attend appointments and hospital admissions on your own and independently communicating your healthcare needs. These are usually encouraged prior to transition along with finding new ways to continue to include your support person in your care. This may mean speaking to them before or after each appointment, to help you remember what to ask and go over any changes moving forward. Taking your own notes during or immediately after appointments along with requesting a copy of your health care plan can also help ease the burden of having to remember everything early on. Continuing to have your friends or family visit you during hospital admissions is also a great way to stay supported without the need for them to stay overnight.

The most important aspect to remember during times of change is to remain proactive in staying connected and open to different types of support. This will help reduce the tendency to close off or feel the need to be fully independent too quickly, as this is not what transition is about.

To do:

- ☐ Make a list of the things I expect to change during and after transition.
- ☐ Complete the list of ways I can help manage these changes.
- ☐ Share any concerns I have with my existing cystic fibrosis care team and/or support network.
- ☐ Explore options for connecting with my peers and those within the cystic fibrosis community.
- ☐ Make a list of questions I have for my cystic fibrosis care team before each appointment.

- ☐ Ask for a copy of my health care plan or associated document after each appointment.
- ☐ Continue connecting with my friends and family whilst gradually building my independence.

Knowledge check!

I know and understand...

- ☐ Finding support that feels right for me is important.
- ☐ Asking for help and communicating my needs can make a difference.
- ☐ Embracing change will help me to feel a sense of control.
- ☐ Continuing to access support whilst developing my independence is possible.
- ☐ Where to go for help if I need further assistance or more information.

Online forums and peer support

Some state-based cystic fibrosis organisations host regular online forums where you can meet or just listen to other individuals living with cystic fibrosis and their parents discussing cystic fibrosis related topics. These forums are generally informal and offer a chance to ask questions and learn more about important issues that affect those living with cystic fibrosis. [Cystic Fibrosis Queensland hosts a Community Advisory Committee.](#)

Social Worker services

As part of your cystic fibrosis clinical care team, you will generally have access to a Social Worker or similar. You may find utilising their services more often during transition beneficial. Accessing support can help foster a sense of control over change, so plan to stay connected!