



# How You Can Help Your Family Member Take Charge of Their Health

People with intellectual and developmental disabilities (I/DD) may struggle to take charge of their health.

They may have trouble communicating with their doctors about their health.

Sometimes family may be scared to talk with them about big health issues that are going on.

Families may decide not to tell people about big health issues because they don't know what to say.

As a result, people with I/DD may feel like they don't have a voice.

People may also feel like they don't know what is going on with their own health.

**People who take charge of their health are healthier and happier with their health care.**

They ask questions and get answers from their doctors.

They talk with people they trust about their health and learn about what is going on.

They make decisions with people they trust about their health.



# HERE ARE THINGS THAT YOU CAN DO TO HELP YOUR FAMILY MEMBER TAKE CHARGE OF THEIR HEALTH:



Ask how their mind and body feel each day. Keep notes on how they feel about their health.



Observe any health changes that happen. Make sure to ask others who support your family member to note if they see any changes happening.



Help your family member practice going to the doctor. Role play questions to ask the doctor during an appointment. Make sure to include a question about what health care issues your family member should be thinking about in the future. Write down key points and take notes to the visit.



Prompt doctors to talk to your family member, not you. Reinforce that you are there to listen. Ask the doctor to write down what happened at the appointment and what your family member should do next.



Help your family member find another person who can support their health. This person should be someone that they trust and who can support them with their health decisions for many years.



Think about the future; there are several issues that appear later in life. One of the most significant is dementia. Many people with I/DD, particularly people with Down syndrome, are at risk for dementia. Adults with Down syndrome are more likely to have dementia in their life, with 30 — 40% of people with Down syndrome having dementia by age 50.



Talk with your family member about the future. Many families don't know how to talk about significant health issues like dementia. But, people with disabilities want to know about health risks. Talk with your family about potential risks in the future early, making sure to stay calm and repeat information as needed.



Support your family member to make a plan for the future. Find out more at [futureplanning.thearc.org](https://futureplanning.thearc.org).