

Preparedness for chronic and rare disease management during a pandemic

A case example of a child with Epidermolysis Bullosa

Facing the uncertainty of access to regular services can be confronting for most people as our country puts measures in place to slow the spread of COVID-19. Add the complication of requiring regular medical assistance and access to wound care products or medication for daily management of a rare or chronic illness, and the situation becomes more complex.

Case

Toby is 5 years old and has Epidermolysis Bullosa (EB). EB is a rare and chronic disease with many potential complications. Care requirements for Toby include:

- Daily dressing of wounds on both arms and both legs
- Continuous overnight formula feeding
- Weekly physiotherapy, occupational therapy, and hydrotherapy sessions to help Toby maintain strength and movement
- Weekly dietitian phone call to monitor his eating, weight, and ability to swallow
- Daily medications for pain and infection, and nutritional supplements

Ways to prepare for disease management:

1. Maintain contact with your primary care provider

Contact the person who usually manages your care: GP, Nurse, or care coordinator. Find out when they will be working and how to contact them if they will be working from home or have moved into a new role.

Toby:

Toby's family have made a phone call to his primary nurse and care coordinator. They have found out that his nurse will still be working at this time, and that as his care coordinator is unwell, his case will be managed by another staff member who now has all of Toby's details. Toby's family now has the new care coordinator's details as well.

2. Telehealth

Find out which computer program your health provider is using. Many hospitals require you to be able to access a certain program so that secure networks can be used for video-health.

Many health professionals can organise a secure link for you to have your appointment online. You can access the internet from a phone, tablet or computer. If you have difficulty accessing the internet, find out if your care coordinator, a friend, or a family member can talk you through setting up the program that you need.

Toby:

Toby's family had a practice meeting with their nurse using the home computer. They have also checked their microphone and audio setting for the appointment, and they are now ready for all of their appointments from home.

3. Access to medication and care needs

If you are concerned about running out of your medications, you should talk to your doctor. You may even be able to do this over the phone or through telehealth if you cannot see them face-to-face. Sometimes the doctor can send your scripts straight through to your pharmacy electronically. You would need to talk to your doctor and your pharmacy to see if they can do this. Some pharmacies can home deliver as well.

Contact the organisation that manages any other deliveries such as your wound care products. Questions to ask them can include:

1. Are there any delays in delivery times?
2. Are any of the products that I use regularly low in stock? This would be a good time to speak to your care coordinator and ask them if there are alternative products that you can use when regular items are low in stock.

Toby:

Toby's family has requested repeat scripts for all of his medications. They have been faxed through to their local pharmacy and linked to a home delivery option to limit people coming into the store.

Regular items required for his care that are difficult to obtain from the supermarket; hand sanitiser, disinfectant wipes, moisturiser, and barrier creams, have been added to his weekly pharmacy delivery.

Toby, because of his EB diagnosis, has access to the National Epidermolysis Bullosa Dressing Scheme (NEBDS) and receives a delivery each month from Independence Australia (IA). IA continues to deliver his order each month. Toby's Mother is also looking in to the NEBDS scheme to find out if other items might be suitable for managing Toby's wounds in case there is a supply issue.

4. Prioritising appointments and screening tests

Some medical appointments are urgent and require you to link up with your doctor or nurse. Occasionally these appointments can be more flexible and scheduled at a time when pandemic restrictions have been lifted. Some people require screening reviews done at regular intervals. A monthly blood test required to monitor medication doses needs to remain a priority and communicating this to the pathology centre is important. However, a yearly hearing check-up that is normally done every year in April, could possibly be moved a few months away. Always check with your treating team before cancelling care that is recommended.

Toby:

Toby has had his first telehealth multidisciplinary appointment. He attended his local paediatrician's office, instead of travelling from his regional town to the capital city. The primary treating team at the hospital, his specialist paediatrician from their hometown, the GP from the GP's office and Toby and his family all connected with video and audio link for his appointment.

His care plan was adapted during this meeting, and essential monitoring such as blood tests, weight and swallow monitoring, and wound care were prioritised. Other annual screening that was due this month has been postponed until the end of the year. The care coordinator was used to cluster these appointments and book them already so the family will only have one visit to the capital city.

5. Access to essential goods at home

Some home delivery providers prioritise customers based on isolation or medical need. Isolated, chronically unwell, or those caring for unwell family members can be prioritised for delivery with some companies.

Look into supermarket chains that you may not have used before. Also, volunteer groups can be accessed. Your care coordinator might be able to give you a list of services specific to your condition or age that you can access in your local community.

6. Community and financial assistance

Community or disease specific organisations can support families and individuals with a variety of needs. Assistance can come in many ways, such as; with transport, delivery costs, and linking you to other local agencies, or directing parts of your treatment that may be put on hold to another agency or different part of the health sector that may be able to fill the gap.

Toby:

Toby's father has reduced income this month due to reduction in his working hours at the local store. The family are current recipients of some financial assistance, and they are in communication with the social work team, and a community organisation to find out about increased financial assistance that they may be able to access.

7. Staying well

What factors can make your condition better or worse? Does your condition change with stress, heat, lack of movement? How will staying at home or indoors change your condition? You may need to be creative and find ways to keep up the activities that normally help to keep you well.

It can be difficult to keep up with weekly hydrotherapy or physiotherapy classes at this time. Some clinics and hospitals are being very creative and offering online classes to show you safe ways to try and stay active. You can ask your allied health team if they know of any online websites or apps that can also offer classes for you to do at home.

Toby:

The family have set up an inflatable pool in the back yard to encourage play and movement to replace his physiotherapy sessions. Dance games on the games console have also been a fun way for Toby to do his activities and his family are also joining in.

Toby's physiotherapist from the main hospital has also been in contact online with the family to show some activities that he can try.

In Summary

1. Know how to access your doctor and main care coordinator via telephone or teleconference.
2. Stay in contact with your local pharmacist, for supply of items essential to your care.
3. Speak to any companies that manage delivery of medications, wound care products, special diet or feed requirements or care items. Plan ahead with any items that are hard to access.
4. Use your community support agencies, extended family, or neighbours may be able to assist with shopping or driving and dropping things to your house.
5. Make your health a priority, stay as active as you can, learn about online events, eat well, and register as a priority group for supermarket home deliveries.
6. Ask for help to set up online access to be able to stay in contact with family and friends if you are unsure how to access teleconference sites.
7. Create a social media account - if you do not already have one. Think about linking up to the grandchildren, grandparents, and extended family?

Planning ahead and communicating with your treating team can help you to stay well at this time!