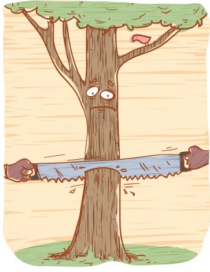


Supporting Family or Friends who receive a diagnosis of Cystic Fibrosis





The diagnosis of a life-threatening illness places a huge strain on families and relationships. It's a whirlwind time of stress and anxiety and a time when special support is needed. Parents want to stay healthy and strong enough to cope with the physical, psychological and financial stress of caring for a chronically ill child. They may also have non-CF children who also need care and attention. Managing CF is complex and can, at times, be overwhelming for parents. Your support and understanding can make it easier for those dealing day to day with the condition.

It is difficult to know what to say and do to help the family during highly emotional times. Sometimes we are afraid we will say or do the wrong thing and this can lead extended family and friends to avoiding contact with the family at the time they need support the most.

Overwhelmed and grieving parents will need time to come to terms with the diagnosis and what this means for their life and they also need time to figure out how to navigate their 'new normal'. They will need ongoing support to help prevent the burnout and depression that is common among caregivers of people with a disability and chronic health conditions.



Cystic Fibrosis affects each individual with the condition uniquely and each family may cope with managing the daily demands of CF differently. Some people naturally find it easier to ask for help than others. Many do not seek assistance with care giving tasks and do not get adequate support.

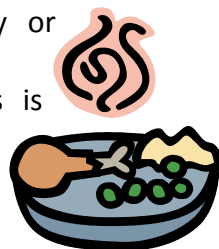
Suggestions of ways you could show support are:



Take some time to learn about CF and how it is managed. Utilise reputable and current information such as from the Cystic Fibrosis Association NZ www.cfnz.org.nz The internet is full of information but not all of it is accurate or helpful to those dealing with the condition. Be very cautious and if in doubt, call the CF Association on 0800 651122 to get the right information.

Ask family members what you can do to help, you may be able to;

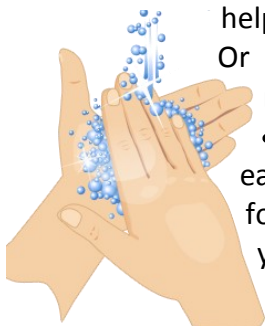
- Get involved - learn how to do physiotherapy on the child to give parents a break
- Make or buy some apple puree and drop it off for the family if this is required for enzyme replacement therapy
- Mind siblings during hospital appointments
- Give the brothers or sisters of the child with CF some special attention and time they also need and deserve
- Become confident with CF management so you can babysit regularly to give Mum and Dad timeout and some much needed quality time together
- Pick up prescription items from the pharmacy or supplies from the hospital if needed
- Prepare meals or food and drop it off. This is especially helpful during unsettling times of hospital admissions and sickness
- Look after household pets. Offer to walk the dog.
- Keep a back up supply of apple puree at your place for impromptu visits and emergency purposes
- Become familiar with terms commonly used by CF families e.g. enzymes, physio, and learn how to say and explain what Cystic Fibrosis is



- Offer to get some groceries or help with household chores
- Care for the carer – do something special or nice for the caregiver. It could be as simple as making a cuppa or cooking a meal. Allow them to recharge their batteries and strongly encourage them to take regular time out for themselves to relax



- Attend hospital appointments or tests for support and be another pair of ears to take in information. This is also an opportunity to meet the CF team that have become a significant part of family life and will be caring for the child over the years.
- Help to provide and support a smoke free environment for the family. If you do smoke, seriously consider giving up or at least respect the family's wishes not to smoke around the child.
- Lend an ear to listen to their fears and worries about CF and their child's future and avoid using clichés that may not be helpful. Provide a shoulder to cry on if necessary. Or someone to laugh with. Laughter is the best medicine.



- If feeling unwell do not visit. Bugs that can be easily cleared by your body may be more serious for those with a chronic illness. Be mindful of your personal hand washing and cough hygiene especially if you have a respiratory infection so you do not pass it on to the family. Ask the family about their expectations and wishes to avoid unnecessary anxiety and uncomfortable situations around passing on colds and flu.

- Be a good friend and don't leave the family isolated. Phone and/or visit. Regular contact is essential for them to be able to communicate their needs and concerns.



- Co-ordinate with other family members and friends to ensure support is available and ongoing
- Arrange via CFANZ to be put in touch to chat with other CF families living with CF dealing with the same situations
- Think about donating regularly to CFANZ to help fund important support services for those living with Cystic Fibrosis

Respect that the family may not always wish to disclose to everyone about their child's condition, especially during the initial time of diagnosis. Allow them plenty of time to feel comfortable and confident to talk about it to those they know less well. Ask how they personally feel about the general public knowing that their child has Cystic Fibrosis.





Empathy, understanding, involvement, encouragement and love are the greatest gifts you can give to a family dealing with CF.

Maintaining a positive outlook helps everyone involved – especially the growing child with CF.

Cystic Fibrosis is a lifelong condition. Don't forget about the family after the initial months of diagnosis and do keep offering to help. They may not always need or ask for your assistance but there will be times in the future you could prove invaluable as a support person.

Our sincere thanks to Cecileah Inns, for her insight and work on developing this brochure

Other recommended resources

CF Information Guide – Cystic Fibrosis Association of New Zealand

www.cfnz.org.nz

Now that we've given you some ideas to get you thinking, it's time for you to make a list of all the ways you think you can help YOUR friend or family member.

When you get stuck about how to help, you can refer back to this list for ideas

My ideas for helping my family member or friend





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