Cystic Fibrosis and Emotional Wellbeing Toolkit

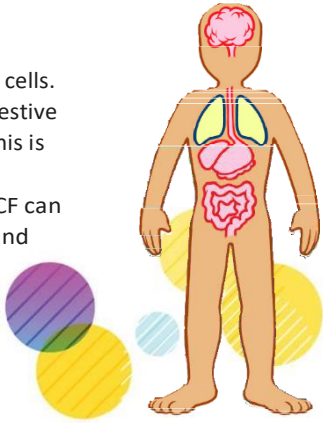
MNIS-SUFFOLK
Medical Needs in Schools

RÆDWALD TRUST

1. Purpose

This wellbeing toolkit is focussed on children's emotional needs that may be exaggerated or emanate from the physical care required for Cystic Fibrosis (CF).This is not to replace the really strong and detailed information available on the physical care of CF and instead we have signposted some of these resources at the end of this toolkit.

2. Definition



CF is a genetic condition which affects salt and water in and out of cells. This leads to an increase in thick sticky mucus in the lungs, the digestive system and other organs. As there is an increase in sticky mucus this is more difficult to clear and has the potential for catching harmful bacteria in the lungs leading to infections. CF can also effect the secretion of bile in the liver leading to irritation and inflammation of the bile ducts.

It is important to understand that:

- the effects of CF differ from person to person, but also day to day
- CF doesn't just affect the lungs but also other organs
- you have due regard for the child or young person to be able to manage their condition independently, but also know when they may need help and support
- whilst CF is a physical health condition it can affect the individual psychologically too

3. Key points

Children with CF are born with it and overtime it adversely affects the cells; it can affect a number of different areas in the body. Treatments are varied and include: medication, physiotherapy, exercise and different nutritional intake.

Children with CF are unlikely to be able to talk face to face with another child with CF due to risk of cross-infection. This may mean that children with CF are restricted in their social interactions in terms of interactions with those that have lived experience of the condition.

Children with CF often need to take medication to help them digest and absorb protein, fats and starch.

Children with CF may have to restrict some activities that put them at additional risk (e.g. playing in mud) and may not be able to participate in other activities due to the timings of interventions during the school day.

4. Information and assessment to inform planning for the individual (IHP)

An **individual healthcare plan (IHP)** is a document that states different ways in which a medical condition may affect an individual in their school life. There are a number of individuals who can support this process, though it should be centred around the child/young person in question and their parents/carers. Below is a guide detailing how individuals/groups may wish to contribute to the formation of the IHP with points for all to consider.

Child/young person's thoughts and feelings to contribute to the IHP as much as possible (e.g.):

- How do they feel about having CF
- For them, which are the most difficult/challenging parts of having CF
- What do they say can be done to make them more comfortable

School

- Where medication can be stored and is accessible
- Whether or not the child/young person can manage their condition independently
- To ensure that a child/young person has access to a space in which to perform physiotherapy.
- Be aware that children's diets may require extra salts and fats irrespective of general Healthy School's policy that may exist
- Ensure opportunities are available for hygiene aspects to be followed (washing hands)
- Understanding that certain bacteria found in muddy water etc. may increase risk towards young people and to provide alternatives for Early Years, continuous provision or for vocational learning.

Clinicians

- Type of treatments/ medication (physiotherapy, nutrition, exercise etc.)
- Clear indication of how much medication is needed and for what purpose
- Information for individual health care plan.

Other sources of information

- Parents/carers should have as much input in the formulation of the IHP as possible
- Websites such as www.cysticfibrosis.org.uk which also include example individual healthcare plans focussed on the physical symptoms of CF.
- Catering information related to dietary intakefor medication calculations

5. Impact of Cystic Fibrosis on emotional well-being

- In addition to typical life stressors, people living with CF manage particular challenges related to keeping well. Staying healthy involves a complex treatment regime that can take up many hours of the day, this can be difficult to sustain and may require a lot of support. One example of physical intervention is airway clearance therapy, which may be needed to clear mucus from the lungs. Along with other medications, most people with CF take oral enzymes with meals and snacks to aid digestion and decrease physical discomfort and pain. Some individuals may need to increase their calorie intake significantly in order to make sure they are a healthy weight and grow well. This may mean they require supplements in the form of tube feedings.
- Acute as well as chronic pain may be a feature of cystic fibrosis – this can have a fundamental impact on a person's mood.
- People with CF may also have more frequent hospital admissions due to acute illness and require intrusive interventions such as intravenous antibiotics. As a result, they could miss out on significant time at school, as well as extra-curricular clubs and other commitments. When children have repeated planned admission to hospital this can contribute to feelings of difference and isolation from peers, missed social opportunities and missed academic opportunities. This can be particularly upsetting if things such as 'Attendance Certificates' are missed if the child has no way of achieving these.

"Acute as well as chronic pain may be a feature of cystic fibrosis – this can have a fundamental impact on a person's mood."

6. Impact of Cystic Fibrosis on emotional well-being (cont.)

- Some children/young people may have lower confidence as a result of CF. They may worry about things such as looking different to their friends, not growing as fast or reaching puberty at the same time as peers, and falling behind with schoolwork and having to catch up later. It is important to try to promote and maintain a positive self-image.
- It is also important to acknowledge the emotional challenges and anxieties that parents/carers may be experiencing; parents will often have a variety of feelings that can present themselves at different times, they may have certain hopes and expectations for their child. The complex treatment routine that CF requires can also be a challenge for parents/carers, as it commands a lot of time, commitment and energy.
- To help the child/young person develop an identity which is much broader than their illness, it is important to be mindful with the child/young person regarding the words used to describe their life, to promote a positive self–image, and to build on and celebrate strengths and progress
- As children with CF grow into teenagers, a feeling of frustration may arise from the responsibility of taking care of their treatments, it is important to pay special attention to children/young people who may be neglecting their treatments as a way of not feeling so different. It is important to find out where the child's current level of understanding their condition is, and to consider with the parents and clinicians how this will be managed going forwards.

"It is also important to acknowledge the emotional challenges and anxieties that parents may be experiencing"

7. Interventions

Finding things tricky

Make sure there is effective communication with parents as well as young person. "X's allocated worker to write regular updates in contact book on X's wellbeing and experiences at school, both positive and negative."

'X will independently undertake physical interventions x/times a day and record in their monitoring book."

There should be an emphasis on celebrating strengths and progress – **praising effort, not necessarily outcomes**.

Not feeling included

Children and young people's activities may be restricted because of their health needs. It is important to make sure that there are alternatives.

"Parents and X will be provided with dietary information 1 week in advanceto help with medication calculation."

"X and their class will be provided with different options relating to outdoor learning."

The IHP should consider how to manage who knows about the illness at school and how the child can be supported to share information: Do they feel confident discussing the issue with their peers? Do they need teacher support to share some information with peers?

Worries about the future

Depression and anxiety may be elevated in children with CF; older children may be especially worried about long-term effects of having CF. Be aware of signs of this and consider signposting for additional support. "X will check in in the mornings with their allocated work and scale their mood from 1-10. Discussions relating to shifts in mood."

Self-conscious

Children with CF may be concerned about the need to cleartheir airways through coughing and have a requirement to use the toilet at all times. "X will be provided with an exit pass so they can leave the classroom." "X will be allowed access to thetoilets located in ____." Feeding difficulties can be an issue amongst children with CF and can generate anxiety in both children and parents. Having a clear understanding about how, where, when and who will help to administer medications at school can help. This should be thought about with the child so it can be done in a way which feels comfortable for them.

8. Scripts

I have noticed that on your healthcare plan it says you are meant todo x, but I don't think I have seen you do it. Can I do anything to make you feel more comfortable?

I can see you are finding things difficultbut I am not sure, can you help me understand?

I can see how hard you have been working on managing the Cystic Fibrosis! Is there anything we can do to help you?

I know we have an end of term event next week, shall wework out what medication youneed so you can feel confident to take part?

I have noticed that in the mornings you have scored yourself a 3 out of 10 for mood.
Can you tell me what mighthelp in raising that number?

9. Progress

- Progress towards all medical outcomes should be discussed and planned with the medical team and the young person's family, as part of the IHP, to ensure all parties are working towards the same targets and goals.
- The IHP should recognise that every child with CF is different and will require a different framework of progress

What might achievement and progress look like?

- Able to attend to own physical health needs
- Is able to choose appropriate meals with minimal support
- Communicates when they feel unwell
- Has an understanding of what activities they may not be able to do or what will need amending to include them
- Continues to meet with key worker with little or no prompting
- Engages in physical health needs independently or reducing support
- Chooses activities which reduce risk relating to CF

10. Resources

www.cysticfibrosis.org.uk

Andy Glynne. "Jasper's Story's Living with Cystic Fibrosis". (2017).

Kairen Griffiths "The World of Sixty Five Roses: An insight into livingwith Cystic Fibrosis" (2020)