

Cystic fibrosis social work service

Information for children, families and carers

We have written this factsheet to provide you with information about our cystic fibrosis (CF) social work service. It explains what the CF social work service is and how it can support you and your child. We hope it helps to answer some of the questions you may have. If you have any further questions or concerns, please speak to a member of your child's CF team or contact us using the details at the end of this factsheet.

What is the CF social work service?

Our CF social work service provides practical, emotional, and social support to children and young people living with CF, as well as their siblings and parents or guardians.

The service is run by a social worker based at Southampton Children's Hospital.

Who is the support available to?

Through the Wessex regional paediatric CF network, Southampton Children's Hospital can offer social work support to children and their families who use the children's CF service at the following paediatric CF centres:

- Basingstoke
- Dorchester
- Isle of Wight
- Poole
- Portsmouth
- Salisbury
- Southampton
- Swindon
- Winchester
- Yeovil
- The Channel Islands

How can we support you?

We understand that CF can impact many areas of daily life, and we are committed to providing compassionate, practical, emotional, and social support tailored to your family's needs.

Our aim is to work in partnership with you to help your family navigate the challenges of CF.

We have included some of the ways that we can help support you and your family below. If you would like to learn more about our service or to access support, please speak to a member of your child's CF team or contact us using the details at the end of this factsheet.

Education, employment and training

We can provide guidance and advocacy (help with getting your voice heard) to help children with CF, and their parents or guardians, access opportunities and training in education or employment. This may include liaising with early years settings, schools, colleges, or employers to ensure appropriate support is in place.

Wellbeing and emotional support

We offer a safe, confidential space to talk about any worries or challenges you or your child may be facing. Together, we can identify goals and put supportive plans in place to help improve wellbeing and build on existing resilience.

Managing daily pressures

Living with CF can bring additional day-to-day challenges. We work alongside families to help manage these pressures and find practical solutions to make life more manageable.

Social prescribing

We can connect you with community-based activities, groups and services that support social, emotional and practical needs. This may include support for loneliness, financial concerns, or mental health and wellbeing.

Financial support and crisis assistance

We can provide advice and support to help you access benefits and other financial support such as grants.

We may be able to assist you to access emergency support, such as food banks, during times of crisis, but we will also work with you to explore long-term ways to help you secure financial stability.

Building connections

We can support families to make connections with others within the CF community, helping to reduce isolation and foster a sense of shared understanding and support.

Housing advice

We can offer guidance on housing-related issues, including accessing suitable accommodation and addressing concerns such as damp or mould that may affect health.

Inclusive support for diverse needs

We recognise and support neurodiversity, disabilities and additional needs. We will work with you to understand how CF care can be adapted, including making reasonable adjustments to better meet your child's individual needs (this may be due to learning, physical, sensory, communication, or other differences).

Coordinating support – ‘Team Around the Family’

We can take a lead role in coordinating a ‘Team Around the Family’ approach. This approach involves bringing together you and your child (if age appropriate) with professionals involved in your child’s care (for example, their teacher or another representative from the school, health visitor, school nurse or housing officer) to create a clear plan of care with your child and family at the centre.

Treatment adherence support

Alongside your child’s CF team, we can help explore any barriers that may affect your child’s ability to stick to their treatment routine and work with you to find practical, achievable solutions, supporting your child to get the most benefit from their care.

Support with transitioning to adult CF services

We can provide guidance and practical support to help build your child’s confidence to ensure a smooth, gradual, and well-supported transition from the children’s CF service to the adult CF service.

Contact us

If you have any questions or would like to discuss anything further, please contact us.

Children’s cystic fibrosis team

Telephone: **023 8120 8973** (Monday, Tuesday and Thursday, 7.30am to 5pm, Friday, 7.30am to 4.30pm)

Mobile: **07789 945490** (Tuesday to Thursday, 8.30am to 4.30pm)

Email: ChildrensCF@uhs.nhs.uk

Useful links

www.cysticfibrosis.org.uk

www.citizensadvice.org.uk

If you are a patient at one of our hospitals and need this document translated, or in another format such as easy read, large print, Braille or audio, please telephone 0800 484 0135 or email PFSH@uhs.nhs.uk

For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit www.uhs.nhs.uk/additionalsupport

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