Reaching Families FACT SHEET Updated October 2023

ADMISSIONS TO HOSPITAL

This fact sheet has been written by parent carers for parent carers.

Staying away from home can be a frightening experience for anyone, especially if we are unwell, around people we don't know, and things happen to us without any warning. This is how in-patient treatment might seem to a child but there is a lot we can do to make stays in hospital better.

Preparing for a hospital stay

Check whether your child really needs to be admitted. Sometimes disabled children are admitted for a minor ailment that could be treated in the community. Could your GP be supported to feel more confident about managing your child's everyday health needs? If your child's condition is likely to be unstable over a long period, try to negotiate an open admissions policy with the hospital, rather than using A&E. Familiar faces are reassuring.

Ask if the hospital has information or support to prepare children for hospital. Some hospitals will have a picture book or website that you can look at. Or they may have specialist staff who are trained to help your child prepare for a visit beforehand. See the 'Ask about' section below.

Try to be honest with your child. Let them know that some days are likely to be painful or frustrating. Some treatment will hurt and sometimes they can't choose.

Ask about staying with your child in hospital. Children have the right to have their parents stay with them in hospital. You can stay with your child through any difficult procedures like being in the anaesthetic room until they go to sleep before surgery or in the recovery room afterwards.

Prepare a folder of important information about your child. You can share this with hospital staff once they're admitted. Lots of hospitals now have a **'Health Passport'** for you to complete to help staff easily learn how your child communicates, their toileting needs, how they show pain, etc. See the 'Ask about' section below.

If your child is having an operation, ask if they can be first on the list for theatre. Your child may find it harder to cope without food or drink before a general anaesthetic. If they are likely to be distressed or confused, it's OK to request the earliest theatre slot but you may need to be assertive.

Help your child stay in touch with friends and with school by email, it will make returning to school easier if they miss a lot. Most hospitals now have public WiFi so ask about this before their stay. If you don't have a laptop or tablet, see if you can borrow one. And ask about your hospital's teaching service (see 'Ask about' below).

If you have any religious or cultural needs, ask the hospital how they will manage these during your child's stay. Hospitals should be sensitive to this, but it may not occur to staff to tell you what is possible, unless you ask.

During a hospital stay

Expect a safe and secure environment. If a situation feels risky, don't be afraid to explain your concerns. Negotiate what can be put in place to minimise the potential, say, for your child to self-injure or wander off. This may mean staying with your child.

Make sure you ask about the potential risks of different treatments. If you don't, you can't reassure your child or help them make informed decisions. Be sure to tell everyone about any medication your child takes; some lower blood pressure, and new medications may be incompatible.

If your child is on regular medication, check who will administer this while they are in hospital. If you plan to do it, you will need to sign to authorise this. If hospital staff are going to administer meds, expect them to be taken away from you.

Keep sharing information. Don't expect things you have told one department to filter through to the next by the time your child gets there. Be prepared to explain again. Stick important messages to your child's locker or above their bed.

Talk to everyone, whenever you can, so that as many people as possible understand your child's needs, especially support staff. They spend more time on the wards than doctors and are likely to have more time to sit, chat and play, and reassure your child when you cannot be there. Explain to other children in the ward. Get questions out of the way, it lets children get on.

If your child doesn't use speech, explain how they communicate 'yes' and 'no' and show you what they need or want. You may need to teach staff some signs or how to use your child's communication book and, for some children, the importance of asking closed questions, using simple phrases and 'listening on all channels'.

Alert staff to changes in your child's body language, mood or pallor that might indicate they are in pain, too hot or too cold. Not all children can explain how they are feeling.

Help your child to get involved in making choices wherever possible. Medical staff should involve them more as they grow and from 16 they are regarded as an adult in terms of decision making about medical treatment. If you think your teenage child may not be able to make these decisions by themselves or at all, discuss this early with the medical staff as there are guidelines about how this should be handled based on the Mental Capacity Act. If you cannot always be there ask about using an advocate (see 'Ask about' below).

If you are unhappy with any aspect of your child's care speak up. It is best to raise it straightaway with a senior member of staff in the team caring for your child as things can often be sorted out on the ground. But if you remain unhappy there is a clear NHS complaints process. See **www.nhs.uk** and find out more in the 'Ask about' section below.

Leaving hospital

Ask about discharge planning and assessments of need as early as possible. Agreeing who is responsible for funding nursing care, training, equipment, aids and adaptations at home can be complex and take time so it's worth checking that your child's community nursing team are anticipating their needs early on, or your child's stay in hospital may be longer than either of you would wish. Each hospital has its own discharge policy. Ask to see this before your stay if possible. And don't forget to ask about an assessment of your needs as a carer too.

Ask About

- **Contact: By Your Side Service** - The '*By Your Side*' parent advisers can make sure you have the information you need when in a larger children's hospital, including referring families to a rare conditions officer if required. Call the specialist helpline, tel: **0808 808 3555** or visit: **https://contact.org.uk/about-us/what-we-do/our-programmes/by-your-side-reaching-families-in-hospital**.
- **Healthwatch** – is the local independent statutory body helping people to have their say and get the information and advice they need about health and social care. They can advise you on what to do if things go wrong and gather information to help improve standards of care. Call: **0300 012 0122,** go to: **www.healthwatchwestsussex.co.uk**, or email: **helpdesk@healthwatchwestsussex.co.uk**.

- **Hospital passport** – an information form that you can fill in and give to staff telling them about your child or young person's needs. Give a copy to staff at the pre-admission appointment, or on admission. Other West Sussex community services can also receive this Hospital Passport about your child if you wish. Find out more and download a copy from: **www.sussexcommunity.nhs.uk/services/servicedetails.htm?directoryID=16352**.
- **Play specialists** – most hospitals have a team of play staff who can prepare children for hospital admission and treatment through games and activities. They can also distract your child during certain treatments and act as their advocate to represent their views.
- **Reaching Families** – provides training, information & other fact sheets related to this topic. We also offer benefits advice, peer support, a Facebook group & handbook (see below) for parent carers of children & young people with SEND in West Sussex. See **www.reachingfamilies.org.uk**.
- **Teaching service** – many hospitals have qualified teachers to provide lessons and learning materials from across the national curriculum, either at the bedside or in a schoolroom if they have one, ask staff for more information.
- **West Sussex Children's Services** – support from health and social care. If your child is under 18, contact the Integrated Front Door (IFD) for West Sussex Children's Services. Tel: **01403 229900** or email: **WSChildrenservices@westsussex.gov.uk**. For over 18s call the Adults' CarePoint: **01243 642121**, or email: **socialcare@westsussex.gov.uk**. Online referral forms for children's and/or adults' social care are available via: **www.westsussex.gov.uk/social-care-and-health/social-care-support**.
- **West Sussex Connect to Support** – online information about health and social care services in West Sussex: **www.westsussexconnecttosupport.org**.

Further reading and useful links

- ***Making Sense of it All: From Birth to Adulthood*** – Reaching Families' handbook for parent carers of children and young people with SEND in West Sussex. This provides essential information on money matters, including claiming DLA and PIP, as well as social care, health, leisure, travel, education and employment. Go to: **www.reachingfamilies.org.uk/guides.html**.
- **Mencap** – information on hospital stays, hospital passports, health checks and more. Also has a learning disability helpline, call: **0808 808 1111**. Go to: **www.mencap.org.uk** or email: **helpline@mencap.org.uk**.
- **NHS advice** – you can find advice on discharge from hospital at: **www.nhs.uk/conditions/social-care-and-support-guide/care-after-a-hospital-stay**.
- **West Sussex Local Offer** – go to **https://westsussex.local-offer.org** for local services, support and details of *Short Breaks* providers for children & young people aged 0 - 25 years with SEND.
- **What? Why? Children in Hospital** – videos filmed in Scottish hospitals to prepare parents and children for common procedures such as blood tests, as well as more specialised treatment such as physio for cerebral palsy, ECGs and EEGs and X-rays. Go to: **www.whatwhychildreninhospital.org.uk**.