Delirium on Intensive Care

Information for families

Great Ormond Street Hospital for Children NHS Foundation Trust

This leaflet from Great Ormond Street Hospital (GOSH) explains delirium when your child is in one of our intensive care units. It explains what delirium is, how it can be treated and what you can do to help your child and yourself.

It is likely your child has been admitted to one of our intensive care units due to an illness, accident or following an operation. Your child may be at the point where their sedation is starting to be reduced and they are starting to wake up. We know that being unwell and in hospital can affect the memory and thinking of both adults and children. This may become more obvious as the sedation is reduced.

You may notice that your child's behaviour is not as you would expect. They may also be agitated and holding a conversation may be difficult. At these times, parents often say: "they don't seem like my child". We know this can be very difficult for parents. You may find your child's condition frightening.

This state of temporary confusion is called "delirium".

What is delirium?

Delirium is a state of acute confusion that can happen when someone is unwell. It can appear over a period of hours to days in children and young people who are ill or who have had an operation. Children with delirium behave differently than usual, and may react strangely to their environment and people around them. This delirious state is usually temporary. When their physical condition improves, the confusion often lessens and eventually goes away. The confused state can vary in duration from several days to several weeks and is affected by a number of factors such as the severity of the illness, the child's age, and the child's physical condition.

What causes delirium?

The most common medical causes include fever, major operations, infections, brain disorder or injury, metabolic disorders, hormonal influences, side effects of drugs such as pain killers and steroids, heart disease, lung disease, and constipation. There is often more than one cause, and in some cases it is not possible to identify the exact cause.

How common is delirium?

There are no reliable figures for how often delirium occurs in children, but It is estimated that up to 1 in 10 people admitted to hospital for an acute illness experience some form of delirium. In a recent study, researchers found that 1 in 3 children remember strange experiences after an intensive care admission, especially if they had been sedated for two days or more.

Things you might notice in a child with delirium

- **Agitation**
- **Reduced level of consciousness.** They are not as clear-headed as usual, as if everything just passes them by, and it can be difficult to communicate with them . They may not know where they are.
- **Memory problems.** The child does not remember the things you have just told them such as why they are in hospital. They may not be aware that they are not remembering things.
- **Behavioural changes.** As the child's understanding of their surroundings is faulty, their behaviour can be altered. The child can adopt a vigilant (or watchful), suspicious and sometimes even an aggressive attitude. Some children can appear paranoid or mistrusting of those around them. Alternatively, some children withdraw into themselves.
- **Not recognising those around them, even their parents.**
- **Perception and thought disorders.** A delirious child often has an unrealistic and disturbed image of their surroundings, for instance, they may see or hear things that aren't there (hallucinations) or misintepret normal ICU noises (e.g think a machine bleeping indicates a bomb or explosion).
- **Variation over time.** The child's presentation may be very changeable, and sometimes these symptoms can be worse at night.

Managing a child with delirium

Medical treatment

Before treatment, the doctors and nurses will try to determine the medical cause(s) of the delirium as quickly as possible. The confusion should improve as the underlying condition is treated. In the meantime, it is important to ensure the environment is as calm as possible and to help orientate your child to their surroundings. We will try to avoid sedating your child and manage their behaviour without medications if possible. However, in some cases medication can be helpful in reducing the distressing symptoms of delirium or to enable us to provide essential treatment.

The two most commonly used medications are low doses of risperidone or olanzapine and sometimes low doses of intravenous haloperidol, all of which are stopped once the delirium improves. We can also use medications to help sleep at night, such as melatonin. We can provide further information about the medication if you would like this, and if needed, we will involve a child psychiatrist to help us treat your child.

Preventing harm

Sometimes a child who is very agitated may be at risk of hurting themselves, such as by getting out of bed or pulling out an intravenous line. In these circumstances, it may be necessary to take precautions. In case of severe agitation, it is sometimes necessary to place the child on a mattress on the floor, or to use a specialist 'box bed'. The nursing team will discuss this with you if they feel this may be necessary.

How long does delirium last?

It is difficult to predict how long the symptoms of the delirium will last. It varies from hours to days. Some children's symptoms remain for quite some time. However, it is important to remember that delirium is temporary and your child will not remain this way permanently.

What to do if you are concerned both during and after admission

During your time on intensive care, you will have met lots of doctors and nurses who will be happy to discuss any concerns you have about delirium. In addition you may wish to speak with a member of the psychosocial team, such as one of the Family Liaison Nurses or Cardiac Nurse Practitioners, or the Psychologists. You are also welcome to contact this team after discharge if you still have questions or concerns.

If your child has required medication to help with their delirium symptoms, your child may have met one of the GOSH Psychiatrists – please ask them any questions about short term or long term support too.

What you can do to help

Children who are suffering from delirium often have difficulty communicating or making meaningful contact with those around them. Try not to panic. We know it is very hard to see your child this way but unfortunately it is something we see and can expect on intensive care. There are lots of ways you can support your child.

- As your child may be disoriented, one of the most important things you can do is provide reassurance and help re-orientate them: remind them who you are, let them know you are there, where they are, why they are there and that they are safe.
- Let them know the time of day and who else is there looking after them (for example, the nurse's name).
- Try to involve your child in the present moment. For example you can bring their attention to things in the room they can see or touch, explain any noises they can hear (for instance, if a machine is beeping), remind them of mealtimes (saying it is getting dark now, your supper will be coming soon for instance) or offer them water.
- It can also help to bring in familiar belongings such as comforters, soft toys, pictures from home of family, friend and school, or play their favourite song, or look through a magazine they like.

If they are sleeping more in the day but not at night, you can try to help reverse this pattern by keeping curtains open in the day if possible and engaging their attention as much as possible.

Speak calmly in clear short sentences so they can understand. For example, keep questions simple: ask "Did you sleep well?" instead of, "Did you sleep well, or were you often awake?".

It's best not to debate with your child about what is or is not real. If they are scared, try to be clear that you perceive things differently (reminding them that they are safe). Bring them back to reality by discussing actual events and people around them.

Visits are important, but make sure there are not too many visitors at the same time. Visitors should try to stay on the same side of your child, so they can focus at one point.

Let other family and friends who are visiting your child know in advance what your child is experiencing and encourage them to respond in the same way as you, to ensure consistency. You could give them a copy of this information sheet so they know what to expect.

If your child uses glasses or hearing aids, try to encourage them to keep them on.

Looking after yourself

Although we know it is hard to see your child distressed and not like their usual self, it is important to remember that this is not permanent. In addition, children often pick up on their parents' anxieties and so it is important to try to look after yourself. It is alright to leave the unit, go somewhere else and even enjoy yourself at times. This does not mean you do not care about your child but it is important for you to take time out to keep your own strength up.

We recommend you try to follow the steps below:

- Take occasional walks outside
- Take a break with a friend who is a good listener
- Eat nourishing meals and try to get at least a few hours of rest every day
- Remember people outside the hospital are often keen to help
- It may be helpful to meet with one of our psychosocial team to talk things through at this difficult time. Ask a member of staff if you would like to arrange this.
- Sometimes parents say it is even harder to leave the unit when their child is experiencing delirium but it is important to try to do this if you can. Perhaps you could take it in turns with a relative or friend? Alternatively, please ask the nurses if a member of the psychosocial team or a volunteer is around to sit with your child, so you can have some time out.

After intensive care

We know that children who have been on intensive care may continue to have strange or patchy memories of their time there, particularly if they experienced delirium. Your child may need reassurance that we would not expect them to remember all of their time in hospital, or the circumstances that led to their admission. In addition, many children may experience strange dreams but feel embarrassed about it. It is useful to let your child know this might happen so that they do not worry about it and can talk about their experiences openly with you if they want to.

Further information and support

- www.picupsychology.net/docs/parent%20leaflet.pdf
- www.picupsychology.net/docs/road%20to%20recoveryv2.pdf
- PICU nurse station number: 020 7829 8808
- Family Liaison Nurses on PICU/NICU: 020 7405 9200 ext 6723 or 020 7813 8207
- Cardiac Nurse Practitioners on CICU: 020 7405 9200 ext 5744
- Psychology: 020 7405 9200 ext 5166
- Social Work: 020 7829 8896
- Psychiatry can be contacted through switchboard on 020 7405 9200

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