

Delirium: Top tips for carers and family members

Advice for prevention, identifying the signs and getting help

November 2023

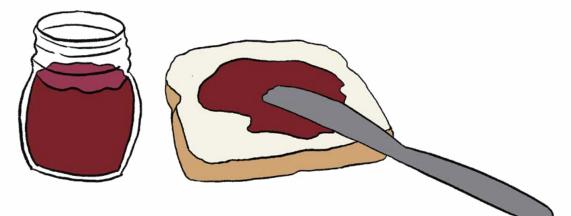


Greater Manchester Integrated Care Partnership This top tip guide includes three main sections covering information on delirium, 8 top tips and where to find useful resources and information.

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Information about delirium

What is delirium?

Delirium is a common condition. It's a sudden new confusion or worsening of a confusion or a new presentation of drowsiness. It mostly comes on as a result of an underlying medical or physiological cause.

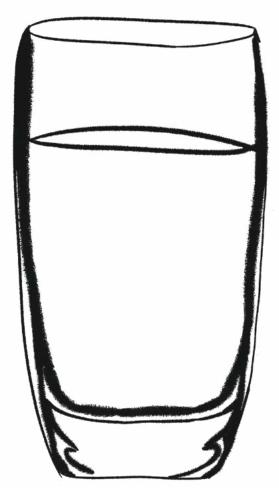
People with delirium may experience disturbances in attention, awareness, increased confusion as well as changes emotionally, in their sleep pattern and behaviour.

It can come on over a couple of hours or days. It's not a permanent illness. Delirium will usually improve once the underlying causes are treated.

How can you tell if someone has delirium?

If a person has delirium they may:

- Not be able to think or speak clearly or as quickly.
- Not know where they are (feel disorientated)
- Be more sleepy or their sleep pattern changes.
- Be distracted and less focused.
- Be more active and on the go.
- Experience upset and distress.
- Not do things they'd usually do e.g. Reduced eating and drinking.
- See, hear or smell things that aren't there (these are called hallucinations).
- Become suspicious and paranoid, which is out of character for them.



What can cause delirium?

There are many things that can trigger a person to develop delirium. These are called underlying illnesses and often it can be more than one of these, for example:

- Pain.
- Infections.
- Not eating.
- Not drinking and becoming dehydrated.
- Constipation.
- Side effects of certain medicines.

Who can get delirium?

It's more common for people who:

- Are aged 65 years and over.
- Experience cognitive impairment, dementia or have had delirium before.
- Have had recent surgery, for example for a broken hip.
- Have many medical conditions, or sight or hearing loss.

People can develop delirium anywhere including in hospital, care homes and living at home.



8 Top Tips

Top Tip 1: Preventing delirium

It's more common for some people to develop delirium as we mentioned in the section above. The following things can help to prevent a family member developing delirium and feel better and get well quickly.



Encourage regular eating habits. If they aren't eating three regular meals a day, try to encourage them to eat little and often.



Encourage regular drinking habits. 6-8 cups of water, or other types of drinks a day is recommended.

There's a higher risk of dehydration in warmer weather so you may need to offer support, assistance and encouragement during this time to ensure they drink enough.



Check and encourage the use of their usual glasses and / or hearing aids.



Encourage exercise and getting up out of bed wherever possible.



Make sure they get a good night's sleep wherever possible.



Encourage going to the toilet regularly, to avoid becoming constipated, such as a diet with ample fibre in it.



Ask a doctor or pharmacist to check if they're taking multiple medicines, or in pain. Certain medicines have side effects that can contribute to someone developing delirium.



Help them to understand and remember where they are. Chat to them, write things down, use familiar things such as a photographs.



Use things they know such as photographs to chat with them Encourage them to engage in activities and hobbies that they like.

Top Tip 2: Spotting the signs of delirium

To reduce the possible impact of delirium it's important to spot the signs as early as possible. We call these 'softer signs of delirium'.

- The behaviour of a person with delirium will change quickly, over hours or days.
- They may be restless and agitated.
- They may be withdrawn and drowsy.
- They might not know where they are.
- They might not recognise friends and family.
- They might not be able to hold a conversation.
- They may see, smell or hear things which aren't perceived by their family, or be suspicious of people around them.

You may have noticed other things about them too, which suggest they're becoming unwell:

- They may go to the toilet less frequently.
- They may be hot, clammy, or sweating more.
- They are reporting pain, or look like they're in pain.
- They may be less likely to get up from a chair, or struggling to walk and you are worried they may be more likely to fall.



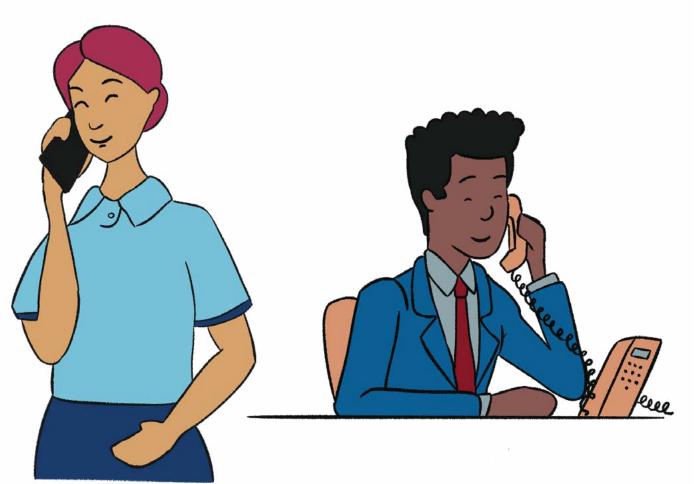
Top Tip 3: Getting help when you need it

It's important to get help early to ensure the best recovery from symptoms. Here are some options if you need to get help:

- The first point of contact may be the Urgent Care Team (also called Crisis Response Team)
- Your general practitioner (GP)
- Call 111 if you are calling outside of normal working hours.
- Call 999 if you think they may need to be seen by the ambulance service.

Here are some tips when you are making the call and asking for help:

- "I'm calling about my family member"; state your relationship.
- "My concern is that they may have delirium".
- "They're showing unusual or out of character behaviours, for example XXX when they would usually YYY".
- Give some examples of changes, such as, "sleeping all day, or restless and on the go, not following simple instructions".
- Talk about how long they have had these symptoms for.
- Talk about what you've done so far to help them.
- If the person is deteriorating and changing over time, provide the details of this and the length of time, so they know why you are worried and are asking for urgent help.



Other useful tips

- Make sure you've got contact details for the team, nurses in case you need to contact them again.
- Make sure you keep other family members and friends updated so that they can offer additional support.

Top Tip 4: Identifying the causes of delirium

You may have noticed things that could help in the identification of the causes of delirium.

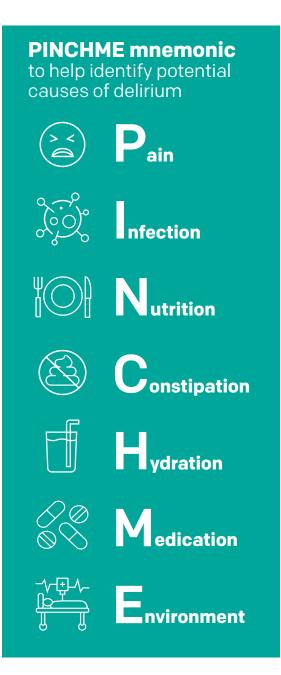
Care teams use a system called PINCH ME to ensure they consider several possible causes of delirium. The image below was developed by the British Geriatric Society which outlines this.

Each letter in PINCH ME helps us identify potential causes of the delirium.

- Pain is the person saying they're in pain or holding themselves like they may be in pain.
- Infection have you noticed the person is showing signs of an infection such as hot to touch, sweating more, going to pass urine more.
- Nutrition have they reduced or stopped eating.
- Constipation is the person saying they're constipated or are there signs such as repeated going to the toilet, pain on going.
- Hydration have you noticed that the person isn't drinking as much as is usual for them, are you struggling to get them to drink.
- Medication have they started any new medication where side effects may be contributing.

In some people there may be more than one cause, so we use PINCH ME to make sure we consider all causes.

Use the image to the right to help think about any physical signs or change in behaviour you've seen in your family member.

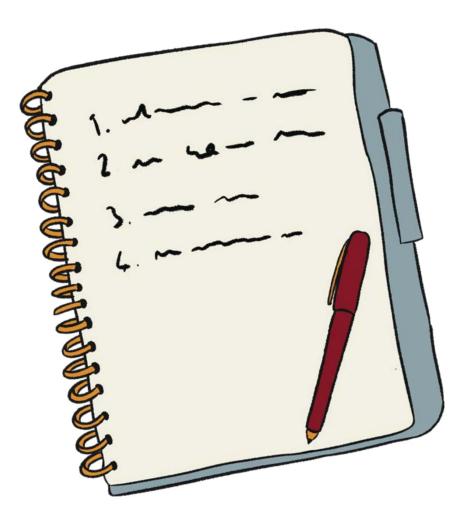


Top Tip 5: Things you can be doing to help

There are a number of things that you can be helping with as a family member or carer:

- You can help to prevent the delirium from getting worse.
- Follow the suggestions for Tip 1: Preventing delirium.
- Make notes of changes in behaviour and times so that you can share this information if needed, if they improve or deteriorate.
- Talk to your care team about how they can support your family member to remain where they are for their care and treatment.
- Make sure you have the contact details for the person's health and or care team. This is in case you need to contact them again.
- Make sure you keep other family members and friends updated so that they can offer additional support.

Delirium will usually improve as the underlying illness is treated.



Top Tip 6: Support when living in a care setting

If your family member is in a care setting, such as a care home or supported living; here are some suggestions of actions you can take:

- Talk to staff about delirium using this top tips resource.
- Talk to staff about the importance of knowing what is normal for your family member; so that signs of delirium can be spotted early.
- Talk to the staff about a prevention plan.
- If your family member has had delirium before they could be at higher risk of getting it again.
- Ask what could be put in place to get them seen quickly if they develop delirium.
- Ask what support could be in place to prevent them from going in to hospital.
- Ask if your family member would be able to stay in the care setting, if they develop delirium.
- Who can the care setting contact as one nominated family member during the day and possibly at night.
- Are you able to visit more often and help with eating and drinking support if it's needed.



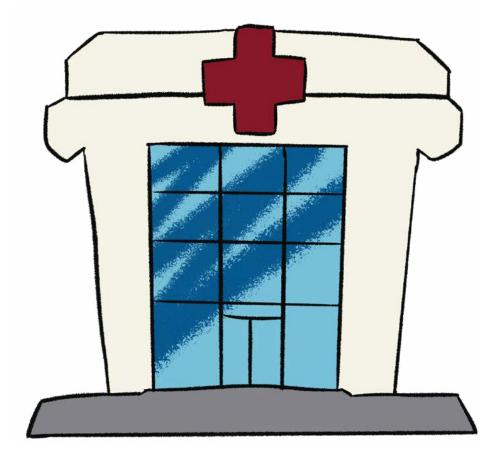
Top Tip 7: Preparing for a hospital admission

There are times when someone with delirium requires a hospital admission.

Here are some of the things you can be doing to prepare for this and things to be asking about.

Before an admission

- Complete a 'This is me' or something similar such as 'Getting to know me'; this provides a detailed picture of your family member which will be very useful for the hospital staff. Include all relevant past medical history in this information if you can too. It's intended to let the staff know, how your family member presents when they don't present with symptoms of delirium.
- This will enable the hospital staff to consider that the symptoms are delirium rather than mistaking them for a dementia type illness or a deterioration in someone's dementia (if they have a diagnosis already).
- Have a number of copies ready of your completed forms and keep hold of the original, so you can make further copies.
- If you have a lasting power of attorney for health and welfare that's been registered, this will need to be shown to the hospital staff looking after your relative or cared for person.
- You will have to show the original. However, it's useful to have a few copies that could be left with the hospital staff to be added in to the medical notes.



- We know that music can impact on our mood, thinking and behaviour. Music can help some people when they're upset, disorientated, and confused. You may want to think ahead and discuss a play list of songs in case you can play these in hospital.
- Some hospitals have devices you can borrow whilst in hospital and you can ask the staff to load these songs onto the device and play them.
- You may be happy to have a device from home with these songs on; that could have headphones attached.
- A reminder too, in case you aren't aware of John's Campaign which supports family visiting for people affected by dementia. You can find out more via the website here: **johnscampaign.org.uk**

During the admission

- Have a clear plan with your family members as to who'll be the lead contact for the hospital staff; make sure that person has all the information they need to be giving a picture of what is the normal routine and recent events leading to the admission.
- Provide the contact details of the person that can be contacted and when they can be contacted. There may be times when the hospital may want to ring out of hours for example, would that be okay?
- There are dementia practitioners in most hospitals in Greater Manchester. These range from Dementia Specialist Nurses or are



called Admiral Nurses. They can be a great support if you are worried about your cared for person. Ask if there are contact numbers for these nurses or practitioners.

• If you aren't getting the information that you require, or after trying to speak to people you feel you aren't being listened to; there are Patient Advisory Liaison Services in all hospitals. You can ask the ward for their telephone number or can be put through via the hospital switch board.

Top Tip 8: Raise awareness

As a carer or family member, you'll have unique insights to share, and health and care staff will be interested in hearing your stories and experiences.

We know that highlighting lived experiences has more impact and increases the likelihood in securing change and raising awareness.

We have some resources shared with us by people with lived experiences of delirium. You can access these via the webpage link here: **dementia-united.org.uk/ delirium**

• You are very welcome to share these lived experience resources or feel free to speak to staff and provide feedback on your own experiences.

There will be value in using the information contained within this top tips resource to be talking about delirium within your family and in any care setting with staff too.



Useful resources

Please also access and share the available information we have in Greater Manchester as below:

Name of the resource and description	Website access to the resource
Delirium leaflet (long) The leaflet provides information on what delirium is, how you can prevent it, how to seek an assessment and the management of delirium. This includes a blank care plan which is to be completed by whichever team is supporting you if you go on to develop delirium.	dementia-united.org.uk/ resources Scroll down to the delirium resources
Delirium leaflet (short) The leaflet provides briefer information on what delirium is, how to seek an assessment and the management of delirium.	dementia-united.org.uk/ resources Scroll down to the delirium resources
Translated Delirium leaflet (short) We've translated the short version of the leaflet in to 16 languages as a written, film and audio resource, which can be accessed via the Dementia United website.	dementia-united.org.uk/ resources Scroll down to the delirium resources
Community Delirium Toolkit This is for health and social care professionals and provides all the resources that they can use to assess, treat and manage delirium for someone in the community (care homes, own home, supported living).	dementia-united.org.uk/ resources Scroll down to the delirium resources
Hospital Delirium Toolkit This is for health and social care professionals and provides all the resources that they can use to assess, treat and manage delirium for someone in the hospital.	dementia-united.org.uk/ resources Scroll down to the delirium resources
Delirium training resources There are resources that you can click on to watch, or read or listen to that raise awareness about delirium.	dementia-united.org.uk/ resources Scroll down to the delirium resources

Organisations which support those with delirium also help people living with dementia, who are at higher risk of developing delirium

We've provided information and details of how to access these organisations below:

Organisation	Telephone no.	Website details
Alzheimer's Society* To access the 'This is Me' form as mentioned above and resources on Delirium and Support.	0330 150 3456	alzheimers.org.uk
Dementia Change Action Network To access the Personal Wellbeing Plan for Emergencies. There's a Blank form and an example of a Completed form too. Scroll down the webpage for the forms.	dcan.org.uk Click on contact us	dcan.org.uk/projects/ hospitals
Age UK To access information on Delirium and support.	0800 678 1602	ageuk.org.uk
Dementia UK To access information on Delirium and support for family and carers of people with dementia.	0800 888 667	dementiauk.org

Get in touch

Email: gmhscp.dementiaunited@nhs.net

Dementia United website for further information: dementia-united.org.uk