Delirium: a family pack

Seven free guides for families, friends and carers

If the change is happening now

New sudden confusion is a medical emergency. Outside a care setting, phone the local emergency number now. In a hospital or care home, tell staff immediately. Get help before reading this pack.

Find the sheet you need

Print the whole pack, or just the pages you need. Telling the team has two pages so there is room to write notes. The poster is the last page.

Choose A4 or US Letter to match your paper. Print at 100% or actual size. Black-and-white printing is fine.

For accessible web versions and editable Word files, visit deliriumsupport.com/downloads.

What is delirium?

Someone with delirium may suddenly become confused, unusually sleepy, restless, frightened or visibly upset. Delirium is a sudden change in attention and thinking that starts over hours or days. Families often say: "They are not themselves."

Common signs

- Sudden confusion about where they are, the time or what is happening
- Trouble paying attention or following a conversation
- Unusual sleepiness, withdrawing from other people or responding slowly
- Restlessness, fear, anger or visible distress
- Seeing or hearing things that are not there, or new fears or beliefs that are out of character
- Symptoms that may come and go, often worse in the evening or at night

The quiet, sleepy form is common and particularly easy to miss.

Delirium is different from dementia

Dementia usually develops over months or years. Delirium comes on over hours or days and often changes during the day. A person with dementia can also develop delirium. If the person suddenly gets worse, they need medical assessment now.

Words to use

> **"They are not their normal self. This began on [day or time]. I think this could be delirium. Could they be assessed now?"**

What causes it?

Illness, injury, surgery or a change in medicines can disrupt how the brain works. Common causes include infection, pain, dehydration (too little fluid in the body) and difficulty passing stools. There may be more than one cause.

How is it treated?

Treatment means finding and treating the cause or causes. Care also includes safe help with food and drink, movement, sleep, glasses, hearing aids and calm reassurance. No medicine cures delirium itself. In some situations, a doctor or nurse may consider medicine for severe distress or an immediate risk of harm. Many people improve, but recovery may be slow.

Get medical help now

New sudden confusion is a medical emergency. If it begins at home or elsewhere outside a care setting, phone the local emergency number now. In a hospital or other care setting, tell staff immediately and describe the change from normal.

If there is an agreed palliative care plan for treating symptoms and keeping the person comfortable, contact that team urgently and follow the plan.

Read more: https://deliriumsupport.com/what-is-delirium/

Get help now: https://deliriumsupport.com/get-help-now/

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Delirium action guide

What to look for, what to say and what to do now

Delirium is a sudden change in a person's thinking, memory or alertness. It comes on over hours or days. A doctor or nurse needs to check the person as an emergency.

What to look for

- Confused about time or place, or clearly more confused than normal
- Much sleepier than usual, drifting off or responding less
- Restless, frightened, angry or visibly upset
- Newly suspicious of family, carers or staff
- Seeing or hearing things that are not there
- Awake at night and asleep by day

Symptoms may come and go. Nights are often worse. The person may still have delirium even if they seem better for an hour. The quiet, sleepy form is common and often missed.

Delirium or dementia?

Ask: is this person different from their normal self, and did the change come on within hours or days? Dementia usually develops over months or years. Any sudden worsening could be delirium or another urgent medical problem and needs assessment now.

Words to use

> **"She is normally independent, with a good memory. Since yesterday she has been confused and very sleepy. She is not herself. I think this could be delirium. She needs emergency medical assessment now."**

What to do

- At home or elsewhere outside a care setting: phone the local emergency number now.
- In a hospital or other care setting: tell a nurse or senior staff member immediately, describe the change from normal and ask for a delirium assessment.

If you can, have this information ready:

- What the person was like a week ago
- What changed and when
- Current medicines and recent changes
- Recent illness, pain, falls, drinking less than usual or difficulty passing stools
- Whether this has happened before

Get emergency help now

Phone the local emergency number now for new sudden confusion outside a care setting. In a hospital or care home, tell staff immediately. Tell them if the person is hard to wake, barely responds, struggles to breathe, has signs of a stroke, has had a seizure or head injury, or is getting worse quickly. Mention any blood-thinning medicines after a head injury.

If there is an agreed palliative care plan for treating symptoms and keeping the person comfortable, contact that team urgently and follow the plan.

Read more: https://deliriumsupport.com/get-help-now/

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Telling the team what only you know

A short form for family, friends and carers

Staff may meet the person for the first time when they are already ill. You know what they are usually like. Fill this in and give it to staff, or use it when you speak to them on the phone.

Six useful things to tell the team

1. What were they like a week ago?

2. What has changed, and when did it start?

3. Which medicines do they take? Include anything started or stopped in the past two weeks.

4. Have they recently had a fever, cough, pain, fall or difficulty passing stools, been drinking less than usual, or had an operation?

5. Has anything like this happened before?

6. What is your name and phone number?

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Telling the team what only you know (continued)

Keep this page with the completed form

Also tell the team

- Whether they use glasses, hearing aids or dentures, and where these are
- How much alcohol they usually drink, and whether they have recently cut down or stopped
- The name they answer to, what calms or upsets them, and how they usually communicate

Words to use

> **"They are not their normal self. This began on [day or time]. They are now [give two clear examples]. I think this could be delirium. Could they be assessed now?"**

Get emergency help now

New sudden confusion is a medical emergency. At home or elsewhere outside a care setting, phone the local emergency number now. In a hospital or other care setting, tell staff immediately.

Read more: https://deliriumsupport.com/get-help-now/

Raising concerns with staff

Useful words when a sudden change has been missed or dismissed

You know what the person is usually like. Delirium is often missed, especially when someone becomes quiet or sleepy. Raising a concern is not complaining. It may give staff the information they need to recognise a sudden change.

Three things to say

1. Describe the change from normal, with times and examples. "On Sunday she was doing the crossword; today she can't follow a sentence."
2. Use the word delirium, so staff know what assessment you are asking for.
3. Ask a direct question. "Could a clinician assess him for delirium now?"

Put it together

> **"Dad is not himself. Yesterday he was chatting and joking; today he keeps asking where he is, and he is too drowsy to finish a meal. This came on quickly. I think it could be delirium. Could a clinician assess him now?"**

Staff may use a short bedside assessment, such as the 4AT or another tool used locally. If nothing seems to be happening, ask: "Could someone assess them for delirium now?"

Keep a short note with dates and times: "Tuesday, 6 pm: thought I was her sister. Wednesday, 9 pm: trying to pack." Your notes can help staff see how the symptoms change over time.

If the change is explained as dementia or age

> **"I know she has dementia, but this is different. Her dementia changes slowly. This happened between Tuesday and Thursday, and she is seeing cats that are not there. Could this be delirium on top of dementia?"**

> **"Being 88 does not explain becoming this confused in two days. Last week he was doing his own shopping. I would like him assessed for delirium."**

If you are not being heard

- Explain again what worries you and when the changes happened.
- Ask for the nurse in charge, a senior doctor or nurse, or the senior staff member responsible for the person's care.
- Ask for your concern and the response to be written in the health record.

Report unusual sleepiness urgently. If the person is hard to wake or barely responds, ask a doctor or nurse to check them as an emergency. At home or elsewhere outside a care setting, phone the local emergency number now for new sudden confusion.

Keep asking for help if you are still worried.

Read more: https://deliriumsupport.com/raising-concerns/

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Helping at the bedside

What you know can help staff understand what the person is usually like. If you can visit, being there may help them feel safer. Ask staff what is safe for this person.

If you are there

Sit where they can see you. Say who you are. If they welcome touch, hold their hand. Short, calm visits may be easier than a long or busy visit.

Talk simply

Use short sentences and give them time to reply. Mention the day, place and what happens next as part of the conversation: "It is Tuesday morning. You are in hospital. Lunch is coming soon." Do not test their memory with repeated questions.

If they believe something that is not true

Do not argue and do not agree with a frightening belief. Respond to how they feel: "That sounds frightening. I am here with you." Explain what is happening now in simple words, then talk about something familiar.

Make the bedside easier to understand

- Glasses on and clean; hearing aids in and working; dentures in when safe
- A clock or calendar where they can see it
- A few familiar things, such as photographs, a blanket or music played quietly

Drinks, meals and moving

- Ask staff what the person may safely eat and drink, and whether you can help them move.
- Do not give food or drink if the person is too drowsy to swallow safely.
- Follow any advice about swallowing, limits on how much they should drink, or falls.
- Tell staff if the person drinks less than usual, has a dry mouth or pain, has difficulty passing stools or urine, or becomes unusually sleepy.

When you are not there

Ask how to contact the person or care team, who will give updates and what staff need from you. Take breaks and share visits if you can.

Get help for a sudden change

Tell staff immediately about any sudden worsening or if the person responds much less than usual. If sudden confusion begins at home or elsewhere outside a care setting, phone the local emergency number now.

Read more: https://deliriumsupport.com/how-you-can-help/

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Delirium or dementia?

The differences at a glance

A change that starts over hours or days could be delirium, even if the person already has dementia. A hallucination means seeing or hearing something that is not there.

	Delirium	Dementia
How it starts	Over hours or days. You can often put a date on it.	Usually over months or years. Often noticed when looking back.
How it changes	May come and go during the day. Often worse at night.	Usually slower and steadier. Symptoms can get better and worse in dementia with Lewy bodies. Dementia caused by damage to blood vessels in the brain may change in steps.
Attention	Often poor. The person may find it hard to follow a conversation.	Often less affected in the early stages of Alzheimer's disease. This varies in other types of dementia.
Alertness	May be unusually sleepy, respond less than usual or be unusually alert.	Usually normal in the early stages of Alzheimer's disease. This varies in other types of dementia.
Seeing or hearing things that are not there	This may happen. Seeing things can be frightening.	This can happen, especially in dementia with Lewy bodies.
Cause	A new physical problem, such as illness, injury, surgery or a medicine change.	Diseases of the brain, most often Alzheimer's disease.
What happens next	Often improves when the causes are treated, though recovery can be slow.	Usually changes slowly over time. Treatment and support depend on the type and cause.

When the person already has dementia

People with dementia are more likely to develop delirium. If the person suddenly gets worse, it could be delirium or another new medical problem. Treat it as such until a doctor or nurse has checked the person.

> **"She has dementia, but this is different. On Tuesday she was feeding herself and chatting. Today she can't stay awake. Could she be assessed for delirium?"**

Get medical help now

New sudden confusion is a medical emergency. If it begins at home or elsewhere outside a care setting, phone the local emergency number now. In a hospital or other care setting, tell staff immediately and describe the change from normal.

Read more: https://deliriumsupport.com/delirium-or-dementia/

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Sudden confusion may be

DELIRIUM

Has someone you care about suddenly become confused, much sleepier, restless or simply not themselves?

Clear, free information for families and anyone supporting the person

- What delirium is
- What to do now
- How families can help
- What recovery may be like

Scan the code or visit:

https://deliriumsupport.com/what-is-delirium/

New sudden confusion is a medical emergency. At home or elsewhere outside a care setting, phone the local emergency number now. In a hospital or other care setting, tell staff immediately.

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