



Healthcare
Improvement
Scotland

SIGN
Evidence-based
clinical guidelines

Delirium

A booklet for people who have experienced delirium, and for their carers

PLAIN
LANGUAGE
COMMISSION
CLEAR
ENGLISH
STANDARD

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Who is this booklet for?

This booklet is for you if:

- you are a relative or carer of someone who has delirium
- you are at risk of delirium
- you have experienced delirium.



What is this booklet about?

This booklet explains:

- what delirium is
- how to reduce the risk of experiencing delirium
- what it is like to have delirium
- how it is identified
- how it is treated
- the care provided.

This booklet describes recommendations in a clinical guideline, produced by the Scottish Intercollegiate Guidelines Network (SIGN), about how to reduce the risk of delirium and how to manage it when it occurs in adults. It applies to all care settings: home, long-term care, hospital, and hospice.

The clinical guidance is based on what we know from current medical research. It gives advice based on the opinion of healthcare professionals who are trained on how best to manage care for people with delirium. On page 24 you can find out how we produce guidelines.

There are three different types of recommendations in this booklet.



Strong recommendation
based on good-quality
research evidence



Recommendation
based on the research
evidence



Recommendation
based on clinical
experience

What is delirium?

Delirium is a worsening of a person's mental state that happens quickly (over hours or days). It usually improves when whatever is causing it gets better.

Are there different types of delirium?



There are various types of delirium, sometimes called hyperactive, hypoactive and mixed. The mixed type is when hyperactive and hypoactive states come and go.

In **hyperactive delirium**, the person becomes agitated and restless.

In **hypoactive delirium**, the person is drowsy and withdrawn.

What are the symptoms of delirium?

People with delirium may experience symptoms that include:

- being less aware of surroundings
- being unable to speak clearly or follow conversations
- being confused
- having dreams that may sometimes be frightening and that may carry on when awake
- seeing or hearing things that aren't real
- thinking that people are trying to harm them
- being very agitated or restless
- being sleepy and slow to move or answer
- being reluctant to eat or drink
- having a change in personality.



Sometimes these symptoms are worse in the evenings or overnight. They can get better within hours or days but in about one in five people they last for weeks or months.

What are the factors associated with developing delirium?

Background risk factors

Several factors increase the risk of delirium, including:

- older age (over 65)
- having dementia
- being frail
- having more than one illness
- being male
- having loss of hearing or sight
- a history of depression
- having had delirium before
- alcohol misuse.

Triggering factors

These include infections, side effects of medicines, surgery or injuries.

Delirium is one of the most common medical emergencies.



- It is found in up to 20% of adults in hospital.
- It affects up to 50% of people who are in hospital for a hip fracture.
- It affects up to 75% of patients in intensive care.



How do you reduce the risk of delirium?

Delirium can be caused by the factors set out on page 6. Trying to reduce the risk of developing it should be considered for people in all care settings.



Recommendation based on the research evidence

These steps can help reduce the risk of developing delirium:



Ensure the person has their glasses or contact lenses and hearing aids.



Explain to the person where they are and ensure they have familiar items with them such as photos.



Find ways to help the person sleep (eg reduce noise and lighting).



Help the person to get moving, sit up, or get out of bed as soon as they can.



Keep pain under control.



Encourage the person to drink and eat regularly.



Check that the person is going to the toilet regularly.



Recommendation based on clinical experience

If you are having surgery, you and your family or carer should be told about the risk of developing delirium. This can help you cope if it happens.



Strong recommendation based on good-quality research evidence

If you are at risk of developing delirium, an experienced healthcare professional should check all your medicines to see if anything you take may increase the risk.



A 'Getting to Know Me' form, or something similar, will help healthcare staff take care of the patient's specific needs. There's more about the 'Getting to Know Me' form on page 21.

What is it like to have delirium?

A person with delirium might experience hallucinations (vivid dreams), so they may feel under attack. They may also believe their healthcare team are the ones causing them harm.

The hallucinations may keep them in a constant state of fear. A person with delirium may think much more time has passed than is true in the 'real' world. These beliefs will seem real to the person and they will not be able to tell they are not real.

“It was very distressing to see my Mum so anxious, angry and having hallucinations. I wanted to understand what was happening to her and to know how I could help.”

The following videos give an overview of what it can be like for people to care for someone who has delirium. They help to show the condition from different viewpoints.



These videos can be accessed here: ihub.scot/project-toolkits/delirium-toolkit/delirium-toolkit/video-toolkit/

How is delirium identified?

It is important to identify delirium as soon as possible. Relatives and carers should tell medical staff if they notice anything about the patient's behaviour that is different from usual.

Various tests can help healthcare professionals identify delirium. These may be used more than once, because delirium can develop at any time during a person's illness.



Strong recommendation based on good-quality research evidence

The 4AT tool should be used to identify delirium in patients in emergency departments and other short-term hospital settings.



4AT is a quick test where a healthcare professional will ask their patient some questions, eg what year it is, or ask them to give the months of the year in reverse order. This checks for alertness.



Recommendation based on the research evidence

The 4AT tool could be considered for identifying people with probable delirium in the community, for example while living at home or in long-term care.



Recommendation based on the research evidence

Different tests may be used for patients in intensive care. These are the Confusion Assessment Method - Intensive Care Unit (CAM-ICU), and the Intensive Care Delirium Screening Checklist (ICDSC).

CAM-ICU and ICDSC are checklists that healthcare staff can use to identify delirium.

Intensive Care Units (ICUs) are specialist hospital wards that provide treatment and monitoring for people who are very ill.



Recommendation based on clinical experience

If delirium is found, patients and their family or carers should be informed of the diagnosis.



Recommendation based on clinical experience

If a test shows that delirium is likely, a formal assessment should be made by a healthcare professional who is trained to make a diagnosis.

The diagnosis should be recorded in the patient's notes so that other healthcare professionals are aware of it if the patient is moved to their ward, or goes home.

The healthcare team may do other tests to find out what illness may be causing the delirium.



How is delirium treated?

Delirium can be treated in several ways.



Recommendation based on clinical experience

- Diagnosing and treating the underlying causes of delirium. These include low oxygen levels, low blood pressure, low glucose level (blood sugar), and drug intoxication or withdrawal.
- Continuing to treat other conditions the person has.
- Managing medications the person is taking for other conditions.
- Ensuring the person is sitting and moving correctly.
- Reducing noise.
- Helping the person get a good natural sleep (eg reducing noise and lighting at night time).
- Checking if the person is distressed or agitated. If they are agitated, finding out the cause and trying to treat it (ideally without using medicine).
- Preventing the person becoming immobile, dehydrated, malnourished or isolated.
- Reducing the risk of falling and pressure sores.
- Telling relatives or carers about delirium and helping them support the patient.
- Monitoring recovery and referring the person to a specialist if they are not improving.
- Planning what further care the person may need after leaving hospital.

How is delirium treated? continued

Family and carers can support a person who has delirium. One way is to complete a diary so that if the person cannot remember what has happened, the carer can help them make sense of things when they start to feel better. Below are some other good ways.



When caring for someone with delirium, it is helpful to:

- ensure hearing aids, glasses and dentures are available at all times
- have a gentle and friendly approach, smiling and providing reassurance
- talk and keep the person informed in short, simple sentences
- check that the person has understood you and be prepared to repeat what you have said, if necessary
- try to make sure someone the person knows well is with them, because familiarity helps
- try not to agree with any incorrect ideas caused by delirium but disagree tactfully and change the subject
- keep a calendar or clock (or both) within view
- bring in some familiar objects from the person's home to keep next to their bedside
- remind the person to eat and drink, and help if needed.

Details of support organisations and other places you can find out more are on pages 20–23.

Is medication used to treat delirium?

There is not enough evidence to show whether medicines are useful to treat delirium.

Expert opinion supports using medicines in some situations, such as when patients are very distressed and could hurt themselves or the people looking after them.



Will follow-up care be needed?

This section of the booklet is specifically aimed at people who have had delirium to explain what follow-up care they may get.

What will happen when I am well enough to leave hospital?



Recommendation based on clinical experience

A discharge letter will be sent to your GP. It will tell them about your delirium and say that you need an appointment so you can be reviewed by your GP or the wider primary health care team.

If you have a family or carer who supports you, the hospital team is likely to talk to them about how they can help you after you leave hospital. They will discuss with you and your relatives or carers whether you need extra support and make sure the support is in place before you leave. Carers have a right to have a new or updated Adult Carer Support Plan.

Primary health care team

includes GP, nurses and practitioners and in some places mental health team members.



Information about an Adult Carer Support Plan can be found on the Carers Scotland website here: www.carersuk.org/scotland/help-and-advice/factsheets/carer-support-plans-and-statements

How will I feel after I leave hospital?

You may find your usual activities more difficult. This might be because you are still recovering. When you leave hospital it might take time before you feel you are back to normal. Sometimes, people who have had delirium find that reading a diary that their family or carer kept during their delirium helps to fill in the blanks and make sense of what has happened.

Some people who have had delirium may become depressed or develop anxiety. You should speak to your GP or nurse practitioner if you feel you are becoming depressed or you have any other questions about delirium.

“I never discussed the content of my dreams whilst in hospital. I’m not sure when I was experiencing dreams or when this was delirium. I had over 20 dreams and some are still vivid now. I don’t remember speaking to staff in the ward about these but I occasionally spoke to my family. The vividness of the dreams is beginning to dissipate. My family were writing down what I was saying when I was delirious – I didn’t read this until I was back home.”

“I only found out how I had been behaving and what I was saying when I got home and read the journal my daughter kept.”

Will I need more tests after I leave hospital?

When you see a member of the primary health care team, they may decide you need more memory tests. They may wait a short time to see how your recovery goes. They might also repeat the tests every few months to see how you are doing.



Strong recommendation based on good-quality research evidence

Healthcare professionals may decide that cognitive tests (to assess your memory, attention, language function and mood) would be helpful, especially if you were in the intensive care unit when you had delirium or if you are an older person.



Strong recommendation based on good-quality research evidence

An existing condition that you did not know about might have helped give you delirium. Your healthcare professional may also want to test for this. They are more likely to do this if you are an older person.

Will I get better?

Most people who have had delirium do get better but it may take weeks or months. For a few people, particularly older people, the symptoms do not completely go away. If this happens to you, your healthcare team can give you help.

What support can I get if I need it?

If you have a family member or a carer who helps you, a healthcare professional is likely to talk to them about how they can support you. Details of support organisations and other places you can find out more are on page 20–23.

What if I get delirium again?

Having delirium once increases the risk of having it again.



Recommendation based on clinical experience

The hospital will make a note on your medical records that you have had delirium. This will help them decide what treatment to give if you return to hospital for delirium or another condition.

Where can I find out more?

Websites



Scottish Delirium Association

www.scottishdeliriumassociation.com

The Scottish Delirium Association is a group of healthcare professionals working to improve the care of people with delirium by providing education, promoting research and raising awareness of the condition.

Critical Care Recovery

www.criticalcarerecovery.com

This is a website developed by the NHS to offer information, advice and support on recovery after intensive care.

Minded for Families

www.mindedforfamilies.org.uk

This is a website with videos and information to raise awareness of what delirium is and help older people and those around them with how to deal with it.

Carers UK

www.carersuk.org

The website has a directory containing contact details for local carer organisations, support groups and social services departments.

Information leaflets



THINK Delirium

ihub.scot/media/5958/20190312-delirium-leaflet-3-0-web.pdf

This is a patient information leaflet developed by Healthcare Improvement Scotland along with NHS staff.

Alzheimer's Society

www.alzheimers.org.uk/get-support/daily-living/delirium

This is a web-based patient information leaflet on the effects of delirium, treatment and what happens afterwards. It also includes patient experiences.

Alzheimer Scotland

www.alzscot.org/our-work/dementia-support/information-sheets/getting-to-know-me

The 'Getting to Know Me' form was designed for patients with dementia. It is completed with information about the person's likes and dislikes and needs. It is held with the patient's notes to allow staff to provide the best care possible.

Information leaflets



Dementia UK

www.dementiauk.org/delirium

This web-based leaflet describes the symptoms of delirium and gives suggestions of what carers can do to help a person with delirium.

Marie Curie

www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/symptom-control/delirium

This web-based leaflet focuses on delirium occurring towards the end of life. It describes causes, and offers advice on what carers can do and when to seek expert help.

NHS website

www.nhs.uk/conditions/confusion

This is a web-based information leaflet on when to contact a GP or phone an ambulance if someone is showing signs of delirium.

Royal College of Psychiatrists

www.rcpsych.ac.uk/mental-health/problems-disorders/delirium

This is a web-based information leaflet on signs and symptoms, treatment, and what may happen after a person has had delirium.

Telephone helplines



Alzheimer Scotland

helpline@alzscot.org
0808 808 3000

This helpline provides information and emotional support to people with dementia, their families, friends and professionals.

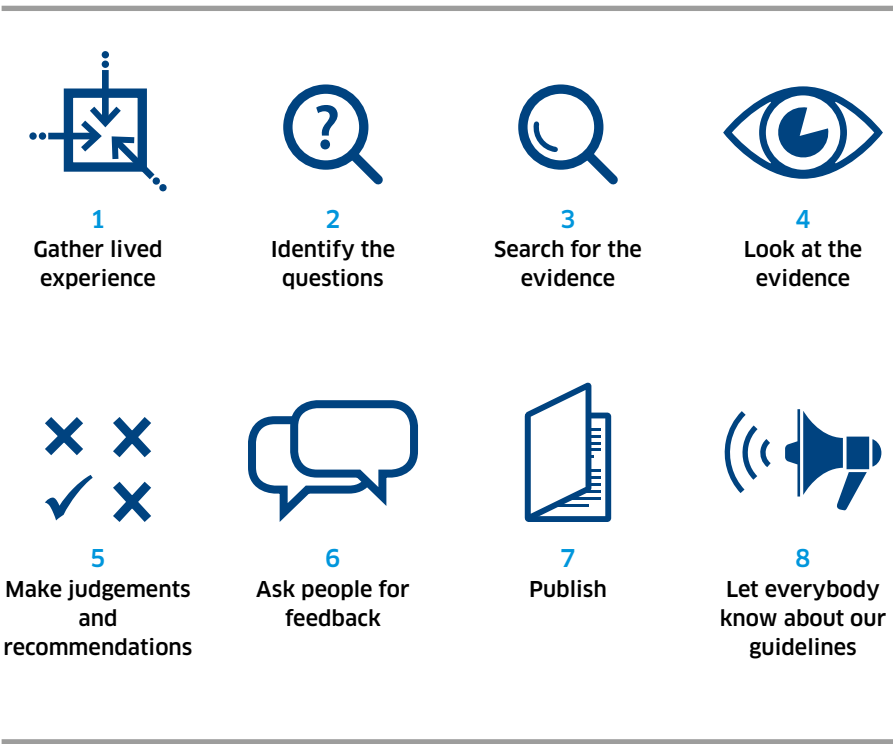
Dementia UK

0800 888 6678

This helpline is available to give support to carers or anyone with dementia.

How are SIGN guidelines produced?

Our guidelines are based on the most up-to-date scientific evidence. We read research papers to find evidence for the best way to diagnose, treat and care for patients. If we cannot find this out from the research evidence, we ask healthcare professionals to use their clinical experience and judgment to suggest treatments.



How are SIGN guidelines produced? continued

You can read more about us by visiting www.sign.ac.uk or you can phone **0131 623 4720** and ask for a copy of our booklet 'SIGN guidelines: information for patients, carers and the public'.

The Scottish Intercollegiate Guidelines Network (SIGN) writes guidelines which give advice for healthcare professionals, patients and carers about the best treatments that are available. We write these guidelines by working with healthcare professionals, other NHS staff, patients, carers and members of the public.

We are happy to consider requests for other languages or formats. Please phone **0131 623 4720** or email sign@sign.ac.uk



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