Huntingdon Road Surgery Patient Participation Group Open Meeting.

Cognitive issues after treatment in intensive care (with or without covid).
Advice for family and friends on services to facilitate hospital discharge and access ongoing support if/as required.

15th April 2021, 1pm - 2pm, zoom.

Speakers

- **Sara Rodriguez-Jimenez,**
  Head of System Operations Room, Urgent & Emergency Care, Cambridgeshire and Peterborough Clinical Commissioning Group.
- **Jane Fowler,**
  Transfer of Care Team Manager, Social Services, Cambridgeshire County Council.
- **Nicky Brady,**
  Operations Manager for the Community Intermediate Care Service, Cambridgeshire and Peterborough Foundation Trust.
- **Alison Wilkinson,**
  Dementia Nurse Consultant, Cambridgeshire and Peterborough Foundation Trust.

Minutes

Jennifer Deegan, checked by Sara Rodriguez-Jimenez.

Audience

The meeting was widely advertised on local community email lists and was open to all registered patients.

Talk content

Delirium is common in elderly people who have been admitted to hospital. Once a patient has experienced delirium in hospital, it is likely that they will experience it again on further readmissions.

Delirium can take the form of hallucinations, in which the patient can see other people and things which are not real. These people and things may be mixed in, and interacting with, other people and things that are real. The patient might frequently see children, and may also see friends and relatives.

The hallucinations can be quite cheerful, and may draw on happy memories of previous life experiences, even in the distant past.

Occasionally, patients may experience “distress in delirium” in which the patient maybe really anxious and frightened, and this can also be frightening for family and friends who may be trying to comfort the patient.

This is especially tricky in covid lockdown, as the family cannot visit the patient. They may not be able to communicate clearly to health and care professionals the patient’s background and history. They also may not know whether the things that the patient is seeing, and talking about on the telephone are actually there in the room or not.

The discussion today was about how friends and relatives can help a patient in hospital who is experiencing delirium, and about what teams and resources are available for support to patients and family after discharge.

For the bulk of the information presented, please see the slides, which are included at the end of this document.

Below are some additional practical points that were considered.

Diagnosis of delirium

Delirium, or an acute confusional state, is usually first diagnosed in the acute admissions ward. This is the place where the patient often goes first after admission to A&E. Clinical staff assess the patient and find out whether they are showing signs of delirium. In considering this, they need to know what the patient's normal state is, and in this regard, information from family can be really helpful.

Practical advice for family in case of further hospital admission.

If a patient has previously experienced delirium in hospital, they are more likely to experience delirium again during further hospital admissions. In order to prepare for this, there are a few things that are really useful to do.

1) Collateral history document

It is helpful to have a document ready that contains the following information. This is to send with the patient in case of an admission. This is particularly useful during covid lockdown, as a patient may not be accompanied by a family member.

- Name, address, date of birth, NHS number, hospital number, next of kin contact details.
- List of medical conditions, allergies, medications.
- Description of normal cognitive state.

It is also helpful to include a piece of paper with photos of close family, including names and phone numbers. This is nice for the patient to have as it will be something familiar that can help them if they are confused, but also helps the clinicians to interact with, and assess the patient.

Put together, this is called “collateral history” and gives the clinicians a picture of the patient's normal state, so they can more quickly work out which parts of the clinical picture might be new problems that need to be addressed.

It is also good to send eyeglasses, false teeth, and some familiar objects, as the absence of these can exacerbate the confusion or challenges for the person experiencing delirium.

2) How to describe normal cognitive state

It can be challenging for family members to describe normal cognitive state. It's tempting to use general terms like “a little slow” or “very anxious”. However, it is most helpful to clinicians if the family members can be really specific about what has changed, when it happened, and whether the change was sudden, or came on slowly.

The example given during the talk was a lady who had been a keen cook for years. She had a normal way of making sausage rolls, that had recently changed.

One day she changed from making one long sausage roll and cutting it into pieces, and instead made lots of individual sausage rolls, rolling up the little strips of pastry around sausage meat, one at a time.

By giving this very specific information, together with the time when the change occurred, and the suddenness of onset, the family gave the clinicians the information that they needed in order to make a clear diagnosis.

When giving clinicians a sense of the patient's cognitive state, it is helpful to be quite specific like this. It is a good idea to think about memory, behaviour and cognition (knowledge and comprehension).

3) Look for the underlying cause of delirium

Delirium always has an underlying cause, and if this can be identified then it helps prevent reoccurrence.

After a first episode, it is a good idea to have the patient assessed by the community memory assessment service, if the patient has not been assessed already by the psychiatric liaison team whilst in hospital. Referral to the community memory clinic is arranged by a GP. If there is an underlying cognitive difficulty, then having a clear diagnosis will really help clinicians who are caring for the patient during a later episode of delirium.

If the patient needs assessment after hospital discharge, it is a good idea to wait for a few weeks after discharge, as sometimes delirium resolves once the person is back at home in his/her familiar surroundings. It is helpful to give the person time to stabilise to a new normal.

If a diagnosis of delirium is provided in or out of hospital, it is good to ask for a leaflet, or some written guidance on the condition, and a list of resources available in community for patients and carers in the event further help and support may be required.

Delirium can also be caused by things like dehydration, infection, pain, and sleep deprivation, so it's good to consider these too, if delirium is ongoing at home after discharge.

Caring for a delirious patient at home

A medically stable patient, with some remaining delirium, can be discharged home or sent to a community rehabilitation bed until their delirium is substantially improved. The decision is person-specific and very much based on the individual's needs and personal circumstances.

Often, delirium will then get radically better shortly after the patient returns home. Family members frequently comment that it is completely gone shortly after discharge, and are keen to bring the patient home as soon as possible, as they know this will be the case.

However, delirium doesn't always get better in a short time. There may be some residual difficulty, or longer term cognitive problems may be identified and diagnosed as a result.

Delirium can be challenging to cope with at home after hospital discharge, with a family member as the carer. It is often more challenging in the evening and night time. If delirium becomes too difficult to cope with, then the carer can phone a GP and ask to be referred to the Crisis Team (Dementia/Delirium Team) and they can provide help. A GP can also offer help and advice on medication and any other clinical needs.

If symptoms do not settle after some time, and challenges remain in the day or night time, it may be appropriate to consider alternative care settings such as a care home, where there staff are available 24/7 to provider care and support. This is less demanding than a single family member trying to provide 24/7 care for months or years.   In this circumstance, your GP can make a referral to the appropriate services to assess care needs.

Carers

Under the Care Act 2014 rights for carers became recognised in law. Carers can receive an assessment in their own right, as well as in their capacity as a carer. The later is called a “carer assessment” and can provide all sorts of help for the person who is caring for someone in this situation.

What else?

It is a really good idea to set up Lasting Power of Attorney documents, for both medical and financial decision making, so that the person who struggles with delirium has someone to make decisions for them, if they cannot do it themselves.

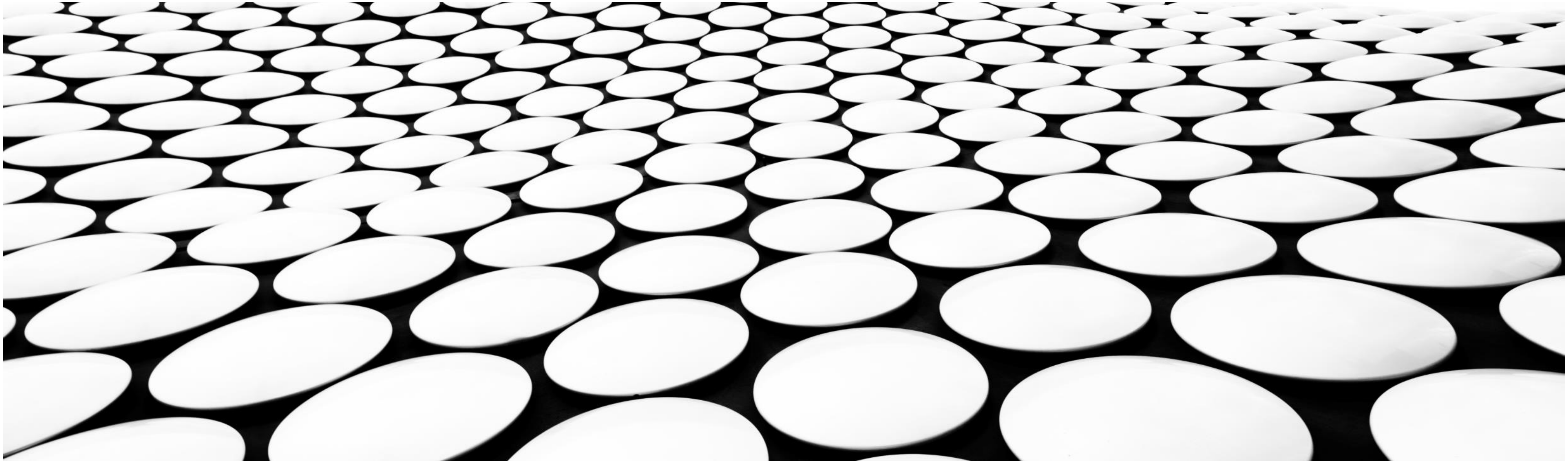
Generally there might be one person who has the principal power of attorney (perhaps the spouse), and one or two others who are a backup (perhaps the adult children). The person with principal power of attorney is in charge of decision making, unless they too are incapacitated.

Once this is set up, it is a good idea for the patient to talk to the family members about what preferences they might have, in the event of critical illness. For example, how good at quality of life would they be prepared to accept after treatment of a really serious illness. It can be very difficult for family members to work this out amongst themselves, when the patient cannot give their views, so a prior discussion is very helpful.

After the meeting, one of the audience members mentioned that this book is helpful: The Book About getting Older (for people who don’t want to talk about it)’. By Dr. Lucy Pollock.

DISCHARGE PATHWAY FOR DELIRIUM

CAMBRIDGESHIRE AND PETERBOROUGH HEALTH AND SOCIAL CARE PARTNERS



WHAT DO WE MEAN BY DISCHARGE PATHWAYS?

- When patients are admitted to hospital a tentative “Medically Fit For Discharge” date should be set. Depending on the patient circumstances, the likelihood of that person needing support on discharge should also be considered at that point for early planning.
- For patients that require on going support following their hospital stay, health and social care professionals will work together to determine which services are best placed to pick up care in community. We refer to the different services as discharge pathways and they are split between:
  - **Pathway 0** – no formal care required but voluntary sector may help (i.e. help with shopping, getting the heating turned on, etc)
  - **Pathway 1** – the person goes home and they receive support at home for a limited period of time until they recover. Usually care and therapy – delivered by Reablement or by Intermediate Care Teams. The NHS or the local authority pay for this care.
  - **Pathway 2** – the person is not able to go home and they need to go into a community bed facility for an interim period of time until they get better. This could be a rehabilitation bed in a community hospital, or a designated bed in a care home setting with therapy teams reaching into the care home. The NHS pays for this care.
  - **Pathway 3** – the person needs to have their long term care needs planned for from the hospital. The person may require a care home placement long term or a permanent package of care at home. Depending on individual circumstances, the NHS may pay, or the Local Authority, or the person may be deemed a self funder and they will be responsible for paying for their care.
- Patients with a confirmed clinical diagnosis of delirium are discharged home on **Pathway 1** if their needs can be met at home or on **Pathway 2** . **Pathway 2** is usually the recommended pathway as often patients will not be safe in between care calls and overnight.

THE PATIENT JOURNEY AT PRESENT – DELIRIUM PATHWAY

1. On Admission

Patient admitted, MFFD set, and in some instances, delirium may be identified and confirmed at this stage

2. clinical assessment

If delirium not evident on admission or not diagnosed, a clinical assessment will take place during acute admission to confirm diagnosis of delirium

3. Patient MFFD and ready for discharge

Sometimes delirium resolves whilst the patient is still in hospital. If that is not the case, and the person doesn’t require acute care any longer they will be discharged under Pathway 2

4. Patient goes to a delirium bed in community

At the moment the only facilities we have to support patients with delirium are beds in care homes that can meet the person’s needs. Once discharged they will be reviewed by the CPFT Intermediate Care Service and should be reviewed by the GP covering the home also

5. On going assessment

The patient will be regularly monitored and assessed with regard to the resolution of delirium, and rehabilitated. Long term care planning at the clinically appropriate time is implemented.

6. Discharge from delirium pathway

Once a clinical decision is made as to whether the delirium is resolving or not, planning starts for the long term. Patients may go home with no support, home with support, or to a care home depending on need.

WHAT ELSE DO WE NEED TO CONSIDER?

- Delirium can take time to resolve, it is important people are given the chance to recover and each person is different.
- We are not always able to support patients with delirium at home. This is currently being looked at to understand what services could be commissioned to send people home with support when safe and appropriate to do so
- People can experience delirium with or without an underlying diagnoses of dementia. They may or may not return to the way they were when the delirium is resolved, and care needs could change as a consequence.
- Caring for patients with delirium requires a collaborative approach between physical and mental health disciplines. It is also important to involve social care early in the event the person will require long term support. There is room to improve current practice, and we are always open to feedback and suggestions from patients and their carers. <u>Please tell us what worked or didn't work for you or your loved one.</u>
- Family members and carers also need to be supported. Some patients with delirium can experience significant distress and this is just as challenging and distressing for family members and carers. <u>Don't suffer in silence.</u>

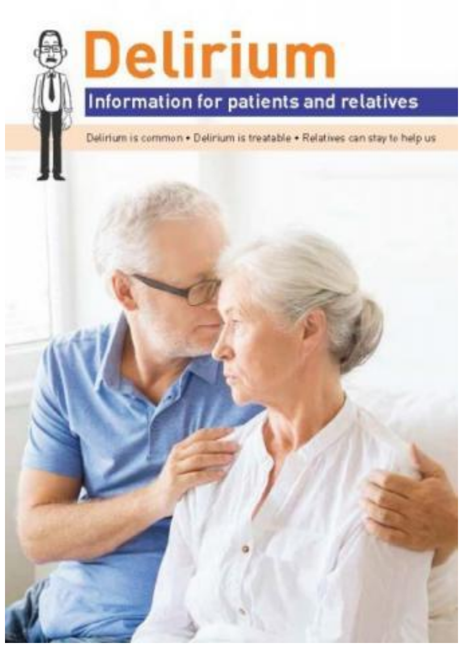
WHAT CAN YOU DO IF A LOVED ONE IS DIAGNOSED WITH DELIRIUM

- Provide to whoever is caring for your loved one a ‘collateral history’, describing what is different about them now compared with prior to the diagnosis and what is different about them over the preceding year. This is useful to identify whether they were showing signs of a reduction in their cognition prior to diagnosis eg memory loss, forgetfulness, periods of confusion.
- Ensure they have their spectacles, hearing aids working and dentures in place and well fitting.
- Provide them with their familiar objects around them that will help orientate them, including a clock. Provide them with their own walking aids.

ADDITIONAL RESOURCES FOR PATIENTS AND CARERS

In Hospital	At Home & in the community
• Discharge planning nurses that are part of the hospital discharge planning team • Social workers that are also part of the discharge planning team supporting patients prior to them leaving the hospital • Psychiatry liaison teams – these are teams of mental health professionals (doctors, nurses) based in the hospital	• Community Memory Assessment Clinic – referrals are either made by the hospital liaison psychiatry teams or by the GP's on discharge when there is the suspicion that the person with delirium has a possible underlying memory problem, such as dementia. • Some people experiencing delirium will need urgent mental health support due to the intensity of their symptoms and GP's can refer to Mental Health crisis teams. • Your GP

RESOURCES



Delirium

Information for patients and relatives

Delirium is common • Delirium is treatable • Relatives can stay to help us

SIGN

Delirium

- https://www.publichealth.hscni.net/sites/default/files/2019-03/Delirium%20leaflet.pdf
- https://www.rcpsych.ac.uk/mental-health/problems-disorders/delirium
- https://www.sign.ac.uk/assets/pat157.pdf

SUPPORT FOR CARERS

Supporting carers

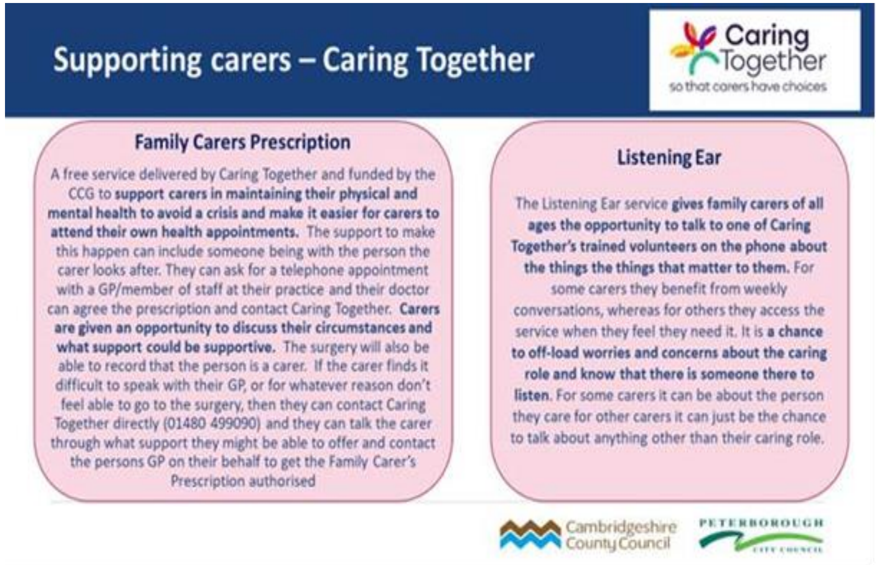
Caring Together www.caringtogether.org

Provide a wide range of support including specialist workers able to offer individual information, advice and guidance, on-line directory of carer services, transitions support for young adult carers, flexible breaks for family carers of all ages, carers emergency planning, immediate support in a crisis, family carers hubs, training and peer support, quarterly carers magazine with lots of information about groups and events organized by Caring Together and other organizations and volunteer led Listening Ear service. They will refer to Adult Early Help Teams (CCC and PCC) for carers assessments if appropriate. Telephone 0345 241 0954

Making Space https://www.makingspace.co.uk/

Offer information and advice on behalf of the Council to carers of adults (18-65) when the cared for person is not supported by the Cambridgeshire and Peterborough NHS Foundation Trust (CPFT) and has mental ill health. This covers a large number of carers. They also offer individualised support to relatives and friends of adults with mental ill health, including one to one support, information on mental health and services which may be available, and peer group meetings. They will refer to Adult Early Help Teams (CCC and PCC) for carers assessments if appropriate. Telephone:01480 211006

Alzheimer's Society
United Against Dementia



Supporting carers – Caring Together

Family Carers Prescription

A free service delivered by Caring Together and funded by the CCG to **support carers in maintaining their physical and mental health to avoid a crisis and make it easier for carers to attend their own health appointments.** The support to make this happen can include someone being with the person the carer looks after. They can ask for a telephone appointment with a GP/member of staff at their practice and their doctor can agree the prescription and contact Caring Together. **Carers are given an opportunity to discuss their circumstances and what support could be supportive.** The surgery will also be able to record that the person is a carer. If the carer finds it difficult to speak with their GP, or for whatever reason don't feel able to go to the surgery, then they can contact Caring Together directly (01480 499090) and they can talk the carer through what support they might be able to offer and contact the persons GP on their behalf to get the Family Carer's Prescription authorised

Listening Ear

The Listening Ear service **gives family carers of all ages the opportunity to talk to one of Caring Together's trained volunteers on the phone about the things the things that matter to them.** For some carers they benefit from weekly conversations, whereas for others they access the service when they feel they need it. It is **a chance to off-load worries and concerns about the caring role and know that there is someone there to listen.** For some carers it can be about the person they care for other carers it can just be the chance to talk about anything other than their caring role.