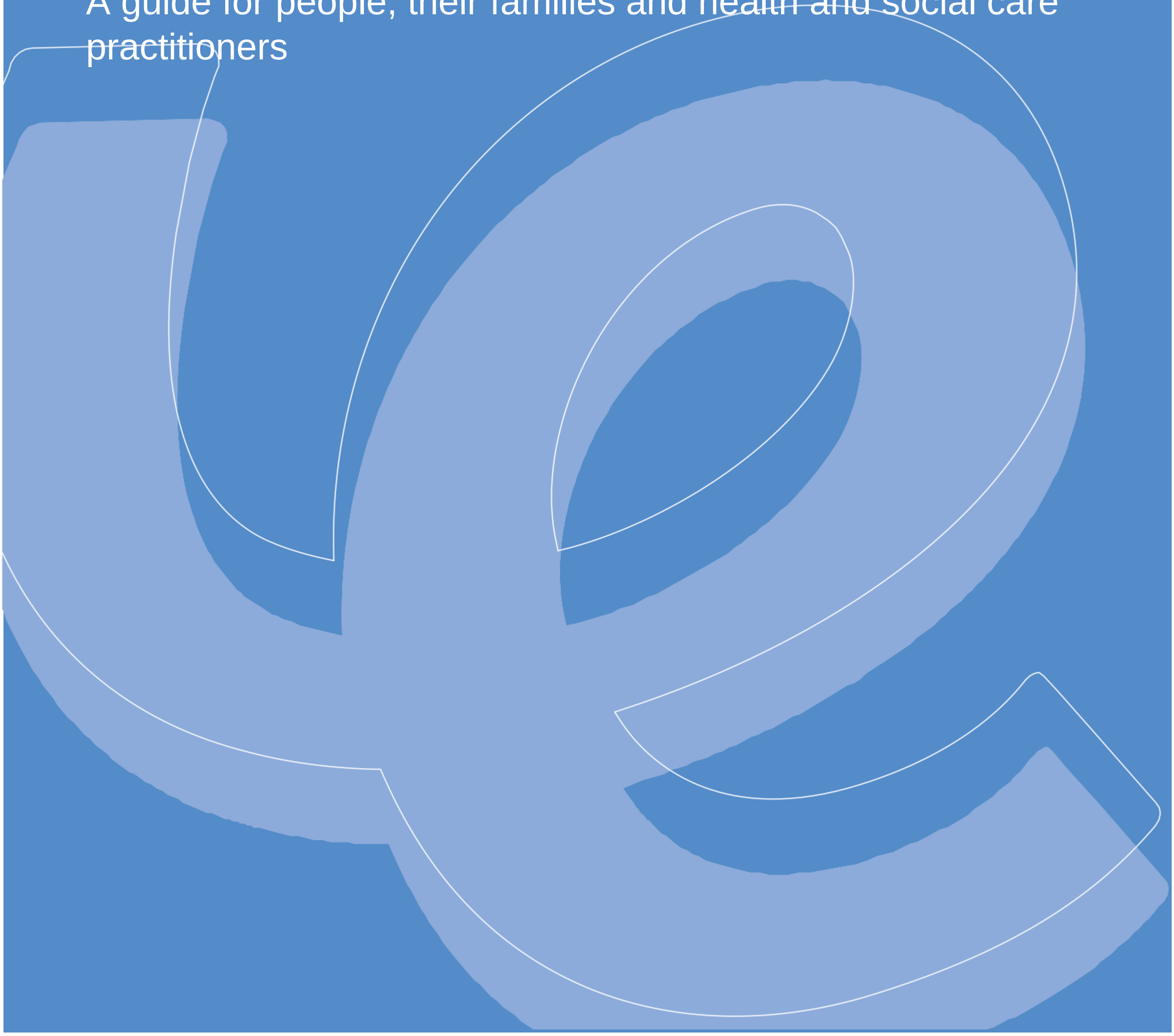
social care
institute for excellence

Get me to hospital: When and how to use the Mental Capacity Act to take a person to hospital for physical health treatment

A guide for people, their families and health and social care practitioners



About SCIE

The Social Care Institute for Excellence improves the lives of people of all ages by co-producing, sharing, and supporting the use of the best available knowledge and evidence about what works in practice. We are a leading improvement support agency and an independent charity working with organisations that support adults, families and children across the UK. We also work closely with related services such as health care and housing.

We improve the quality of care and support services for adults and children by:

- identifying and sharing knowledge about what works and what's new
- supporting people who plan, commission, deliver and use services to put that knowledge into practice
- informing, influencing and inspiring the direction of future practice and policy.

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First published in Great Britain May 2025 by the Social Care Institute for Excellence

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Foreword by the Stop People Dying Too Young group

“Helping people get to hospital is about how you approach them. If you approach them with kindness and respect people are more likely to come willingly. Approach with a caring attitude.” Fiona Regan.

“Show that you care. Talk to them and take your time” Suzie Fothergill.

“Show willing to be able to look after them.” Gavin Barr.

“We are people not machines.” Fiona Regan.

“There is no reason to leave people in pain and in unsafe situations. Catheryne Fairbairn.

“[I]f you don’t plan your always going to fail.” Karen Hughes.

“Paramedics need the information, and they need training. There should be a system in place where they have that person’s information before you go to visit them.” Karen Hughes.

“Do not wait if my life is at risk.” Suzie Fothergill.

“If we are poorly we need help.” Gavin Barr.

“We’ve grown up trusting the NHS and NHS staff. We think you know best. We can be scared to ask for help or support. [You’re] frightened and you don’t know what to do to help yourself.” Lindsey Fothergill.

“I want to live. They won’t take me in the ambulance. I have no access to the ambulance, and it makes me angry. My sister has to take me to hospital. I need a transport ambulance because I can’t get out of my chair. That can take time. To put my chair in an ambulance they’d have to take their equipment out. My life could be over by then. A bed works for most people but not me.” Philip Hughes.

“Lessons must be learned from Jackie’s death and all the other people who have died too young.” Neil Pattinson.

The Stop People Dying Too Young Group

May 2025

Foreword by Margaret Flynn

Most people whose relatives have learning disabilities and other cognitive impairments understand how trauma and medical crises can erupt and change so much in a few hours. It pitches us into heart-on-sleeve territory and leaves us mentally pleading that our relatives will meet kindness, goodwill and compassion at such critical times. If we are not physically present when medical emergencies arise, how might our relatives' ways of being and communicating be interpreted or even known?

While holding tight onto memories of a person's pre-emergency life is one straw to clutch, an especially useful one is the Mental Capacity Act 2005 (MCA). This important guide brings the far-reaching effects of the MCA to the forefront. It addresses the possibility that some people with compromised capacity may decline to be taken to hospital and/or decline medical treatment. The guide's impetus is the untimely death of Jackie Maguire who was so frightened of going to hospital that practitioners did not know how to react.

This guide has been written for families as well as health and social care practitioners. It is an important document because it identifies practical actions with the assistance of people with learning disabilities, relatives, lawyers and practitioners. What's to stop any of us individually and collectively thinking and planning ahead by:

- Asking if services providing support to our relatives have considered Emergency Hospital Admission plans?
- Asking how our relatives are supported to make their own decisions, if this is possible, and how best interests decisions are made on their behalf?
- Where possible, making binding decisions now for the future by appointing a best interests decision-maker through a Lasting Power of Attorney (LPA) for Health and Welfare, for example?
- Becoming stubborn advocates and promoters of the MCA's best interests checklist (as set out in section 4(2))?
- Enquiring of Ambulance Trusts (i) whether their policies concerning restraints may reasonably be used for the purposes of conveying our relatives to hospital, and (ii) what "reasonable adjustments" may be made with, and on behalf of, people with compromised capacity?

Having an LPA applicable to health and welfare decisions, registered with the Office of the Public Guardian, is the Gold Star (see https://www.mencaptrust.org.uk/guides-lasting-power-attorney for information). While it does not close off the importance of collaboration, it hardwires decision-making and closes off the scope for uncertainty and delay.

The publication of this guide is a supersized event and a fitting way of honouring Jackie Maguire.

Margaret Flynn, Chair of the National Mental Capacity Forum

March 2025

Introduction

Each of us, at some point in our lives will become unable to make a particular decision at a particular time and rely on a person to help us to make that decision. These decisions will relate to our health, our welfare or our finances.

The Mental Capacity Act (MCA) governs all decisions regarding care and treatment for people aged 16 and over, who may not be able to make their own decisions. It applies in all settings and situations.

The fundamental **principles** of the MCA protect the rights of individuals, promote dignity, autonomy and respect of the person – their wishes and feelings, beliefs and values; they promote person-centred care, and ensure that where the individual cannot make their own decision, decisions regarding care and treatment are made in their best interests.

- Decisions about taking people with cognitive impairments to hospital can be complex. They involve thinking about the person's own ability to make decisions. For instance, does the person understand the need for medical treatment?
- Can they weigh up the risks of refusing admission or treatment?
- How can they be supported to access the medical treatment they need if their refusal is not based on an appreciation of how serious their condition is?
- If they do not have the ability to make their own decisions about medical treatment, when is it right to use force or sedate someone to ensure that they receive potentially life-saving medical care?

The focus of this guide is to support the individual when they are at the centre of decisions relating to conveyance to hospital and the practitioner responsible for arranging, or undertaking, conveyance of the individual. It also looks to address a potential health inequality where individuals have died from preventable conditions as a result of professionals not using the Mental Capacity Act correctly.

We created this guide with the **Stop People Dying Too Young (the LeDeR programme) - Inclusion North** group because it is important that the people most affected shape best practice.

We also held wide-ranging discussions with social workers, paramedics, care providers, nurses, advocates and family members to identify the key areas that are addressed in this guide.

For the purpose of this guide and relevant discussions, we focus on issues of supporting people under the Mental Capacity Act (and not the Mental Health Act). That is, people who are assessed as unable to make their own decision to be taken to hospital for physical treatment. They require a decision to be made in their best interests. While we acknowledge the additional complexity of people who may be able to make the decision and are reluctant and/or have fluctuating capacity, we want to focus on the specific issues that arose in the case of Jackie Maguire. These are considered on page 6.

While this guidance discusses how to use the Mental Capacity Act in an emergency, we would always advise you seek legal advice if you are unsure and experience complex situations that involve refusal to attend hospital, where possible.

We are also grateful to be able to align this guidance with the release of **NHSE’s national guidance** (**https://www.england.nhs.uk/learning-disabilities/improving-health/**) to support implementation of the Mental Capacity Act in acute trusts for adults with a learning disability.

Thanks and acknowledgements

We would like to thank the following, and everyone who attended our roundtable discussions. This guide could not have been created without your invaluable views and discussions.

Stop People Dying Too Young Group, Victoria Butler-Cole KC, Nicola Kohn, Alex Ruck Keene KC (Hon), Ian Brownhill, Edd Bartlett, Rachel Snow-Miller, Ben Troke, Yvonne Taylor, Chelle Farnan, Anneliese Hillyer-Thake, Larisa Wood, Julie Hall, Helen Edwards, Jamie Stone, Leanne Gelder, Pippa Johnson.

Jackie’s story – why this guidance is needed

Jacqueline Maguire (known as Jackie).

Jackie was a lady with Down’s Syndrome who lived in a residential care home for adults with learning disabilities in Blackpool. She could communicate by uttering one or two words at a time which, together with gesturing and the strength of her personality, meant she usually could make herself known to those who knew her well. She was very independent-minded. She was mischievous and had a wicked sense of humour. In her younger days, she liked nothing more than to see her brothers and sisters get told off. She was the life and soul of the care home and was very popular with the other residents. She had her own sitting room but joined the other residents for meals and social occasions. She always really enjoyed her birthday and Christmas. She liked her food. She loved music – Michael Jackson and Abba were big favourites. She liked to watch TV. She liked looking at fashion magazines. She liked to be taken shopping locally in her wheelchair.

Jackie died on 22 February 2017 at the age of 52. In the weeks beforehand, Jackie suffered symptoms including stomach pains, collapsing, and a sore throat. On the evening before her death, Jackie repeatedly lost consciousness and collapsed. An ambulance crew attended but left after Jackie refused to attend hospital. A General Practitioner (GP) advised that Jackie should attend hospital but that if she refused, she could stay at her care home. The next morning Jackie’s condition had worsened and she collapsed again. She was admitted to hospital, where tests showed her to be severely dehydrated and suffering from an acute kidney injury. She later had a cardiac arrest from which she could not be resuscitated. A postmortem recorded her cause of death as a perforated gastric ulcer and pneumonia.

Jackie’s case is not isolated. and we know from the **LeDeR annual report (2022)**, that the median age of death for people with learning disabilities was 62.9 years and the top causes of death included cancer, flu and heart disease. In addition, if a person with learning disabilities also identifies as mixed ethnicity Asian or Asian British, Black, Black British, Caribbean, or African, it **increased their likelihood of dying earlier by 190%**.

While this guidance has resulted from Jackie’s case, it can apply to anyone who is determined as:

- unable to make the decision to be taken to hospital in an emergency
- reluctant to be taken and needs a decision to be made in their best interests.

For more information about Jackie’s case in the Supreme Court, please see:

R (on the application of Maguire) (Appellant) v His Majesty’s Senior Coroner for Blackpool & Fylde and another (Respondents)

David’s story

David features in this guidance. Although not a real person, David’s circumstances have been created from a number of real-life scenarios. David brings to life the dilemmas and challenges individuals and professionals have had about supporting people who are unable to make the decision to get to hospital and are refusing to cooperate because they lack capacity to do so.

David is 45 years old; he loves to go for long walks, listens to rock music every day and loves to support his local football team, Leeds United. David has the best sense of humour and loves a good ‘dad’ joke.

David is autistic and has a learning disability. David’s home is classed as supported living and he lives with two other people. David has a small team of people who help him with cooking, reminders to get dressed and attend appointments, and help him to understand when he is unwell and needs to see a doctor.

David does not like to see any doctors, he doesn’t like the sound or the brightness of the lights in the GP surgery and crowded waiting rooms and will refuse to enter the building. As a result, appointments are made over the phone and a GP will visit his home if he is very unwell.

While this story is about an autistic person with a learning disability, the scenario and associated actions could be considered for anyone who needs additional support, to get to hospital.

The presumption of capacity is one of the MCA’s principles. However, the courts have made clear that it cannot be relied upon to avoid proper consideration of the person’s capacity if there is good reason to do so. In David’s case, thought needs to be given as to whether:

- his reluctance to go to hospital reflects a capacitous (able to make the decision) refusal to do so, or
- whether it is because he is not able to understand, refuse or weigh-up what would happen if he does not go.

For the purpose of this guide, it has been determined that David is unable to make the decision to be taken to hospital in any transport, when required. That is, he lacks the capacity to make this decision.

Unplanned emergency admission to hospital

Get me to hospital – do not delay if my life is at risk

For the majority of individuals, we anticipate that reluctance to visit hospital settings will be longstanding, are likely to have refused medical intervention before due to negative experiences, trauma or fears. It would be good practice to discuss with everyone, what they want to happen? and what the plan is if they need to go to hospital in an emergency?

In this section, we discuss what to do when there are no available plans in place to support the hospital admission of a person who is unable to make this decision and is reluctant to be taken.

These situations will involve out of hours responses, often between GPs, NHS111, Emergency Duty Teams, and ambulance teams. At such times, there may be no access to advocacy, advice or guidance.

When an urgent decision needs to be made to admit a person to hospital for physical treatment and investigation, a paramedic may reasonably believe that the person is unable to make the decision to be taken in the ambulance. However, if no-one has prepared an emergency admission plan, reasonable adjustments may not have been considered.

In this situation, a decision needs to be made in the person’s best interests. For this purpose, carers and professionals are able to rely on MCA sections 5 and 6, that is acts in connection with care or treatment and limitations. These legal provisions mean that if you reasonably believe that someone lacks capacity to make a particular decision, you can act in their best interests. You need to speak to others and the person about whom the decision is being made to determine what course of action is in their best interests.

Restraint

“Restraint is such an emotive word. I don't think we are talking about a 5 man hold. For my son, it is a gentle push, a couple of seconds of holding his hands or head. Followed by lots of positive praise, etc so he is not in any way traumatised” - Linda Dickinson.

If you decide that the person needs to be subject to a limited period of physical restraint in their best interests, this is permitted by the MCA provided it is proportionate to the risk of harm and the nature of that harm.

It is possible that restraint might last for a sufficiently long time that it constitutes a deprivation of liberty. An ambulance journey might possibly constitute a deprivation of liberty if it is a very long journey or involves very high levels of physical restraint. Concern about whether there will be a deprivation of liberty should not prevent the person being taken to hospital if their life is at risk. In such a situation, the need to preserve life is likely to prevail over any issue about deprivation of liberty.

Even the gentle use of hands to support someone may legally constitute restraint but is almost definitely justified under MCA section 6 which concerns necessity and proportionality.

Any decision that is made in an urgent situation should be reviewed at the earliest opportunity. This is to ensure that any measures taken are appropriate for the individual and the likelihood of their changing presentation as they receive treatment.

The individual should continue to be consulted about decisions that have been taken on their behalf and measures taken at all times, even if views appear contrary to the best interests decision that is being made by the attending ambulance team.

It is acknowledged that there are no national guidelines on who should be called upon to use restraint in these situations. In addition, there are significant variations across organisations. Fact-finding suggests that:

- ambulance teams will not use restraint
- police will not attend for the purpose of addressing physical healthcare needs, and
- if chemical restraint (medication) is required, this is likely to require the input of a critical care paramedic.

Reluctance to be taken to hospital

“When I’ve been in awful pain in the past I’ve wanted to die. I’ve not seen the point in carrying on. But when I’m not in pain I don’t feel like. I know I don’t think straight when I’m in pain and I’m scared I need people to make hard decisions for me to keep me safe.” Suzie Fothergill.

While a known reluctance to be taken to hospital for physical health treatment will require a consideration of measures, it does not mean that practitioners are unable to do anything.

If the person is reluctant to go to hospital, ambulance teams will have to consider whether they are able to make the decision using the best interests principle of the MCA. In such circumstances where professionals reasonably believe that the person requires lifesaving treatment and there is a confirmed mental impairment, caution is advised in relying on the presumption of capacity. Their reluctance should be explored and a timely assessment undertaken. If such an assessment determines that the person is unable to make the decision to be taken to hospital, the person responsible for making the decision will need to make a best interests decision. To do this, where possible, the person’s views, wishes and feelings, and those of people directly involved in their care or treatment, e.g. family and friends, must be taken into account. There is a specific checklist for making best interests decisions (see useful resources on p.22).

If someone holds an LPA for a person’s health and welfare, they would be the best interests decision-maker if:

- it is determined that the person is unable to make the decision to be taken to hospital
- the decision is within the scope of the LPA
- they happen to be there, and
- it is in the person’s best interests.

If the paramedic disagrees with the decision of the LPA for Health and Welfare, and there is not enough time to consult the court, as there is a reasonable belief that the person’s condition is life threatening, the paramedic could still make the decision to convey the person relying on MCA sections 5 and 6 but would advise escalating that decision with a manager as soon as possible.

Ambulance crew will need to check whether the person has an Advance Decision to Refuse Treatment (ADRT), which is a refusal to accept certain medical treatments in the future if specified circumstances arise once the person has lost capacity.

Restraint needs to be considered as a last resort, carried out in the least restrictive way possible and with people who are trained in the use of restraint. It is essential that the Multi-Disciplinary Team (MDT) discussions involve the relevant ambulance trust to clarify their position and policies on the use of restraint and plan for the scenarios considered in ways that may be implemented across organisations.

Do support staff know who is responsible for using restraint to enable someone to receive medical treatment and transition into an ambulance? This question is especially important to clarify when someone resides in supported living so that paramedics and support staff are clear who has responsibility for any restraining actions.

Sedation may be considered if it is in the person's best interests. However, there are cases where extra airway-management may be required to enable safe sedation. The input of a critical care paramedic is desirable but may not be possible depending on the time-sensitive nature of the person's condition.

There was mixed reaction amongst the Stop People Dying Too Young group to restraint being used as a 'plan b'. Two family carers whose adult children both need a lot of support to access medical treatment were more sympathetic to this being part of the plan than people with a learning disability were. It generated a lot of discussion. These are the points that were made:

- There is a need to weigh up the advantages and disadvantages of reasonable short-term restraint versus any side-effects/after-effects of the sedative.
- Who is best to do the restraint? If family are available, can they support this process – one of our family carers goes with her son and his support team and she does a lot of the calming and distracting and holding his hands while the medics carry out their procedures.
- A sedative is a chemical restraint, so both the sedative and the physical restraint should be judged equally, and both used with caution and care.
- Each person should have a detailed plan about what level of restraint is considered 'reasonable'. The family should be involved in this if possible. Also need to define what is 'short-term'. These judgements should be person-centred and based on the person's own history. Do they have a history of being restrained? Is there abuse or trauma connected to this? Is there anything specific to the individual to take into account before signing off on this?
- How long does the sedative work for? What if the ambulance is early/late? How anxious will David be when he is at the hospital? How will this be managed?
- If treatment is ongoing, will David's anxiety increase. Could trust in his staff team be lost if he is being repeatedly sedated and taken to hospital against his wishes/restrained? How is the sedative given? Can he refuse it? What if he starts fighting having the sedative given? Will he be restrained so he can be sedated? Feels like a vicious circle.
- Restraint should be the last option, and as minimal as possible. It should be within agreed boundaries and limitations. It is to keep him safe rather than to enforce a course of action. One family carer described it as "a positive, temporary hold to achieve a bigger goal" and said about her son "I know him best" which is why she attends appointments and supports with this.
- All restraint should be recorded and reviewed afterwards. Did it work? Could it have been avoided?

Preparing for hospital admission when refusal is likely

"It's important to plan ahead for when there might be a crisis. Making plans might be expensive. We know that preparing people for medical appointments helps them get to hospital. Little things like walking by the hospital or going the other hospital, going into the hospital for a cup of tea. All these little things can prepare someone and help them have less fear of the place."

"We worry about our loved ones. We need to know people look after them when we can't." Linda Dickinson.

"The reasonable adjustment flags are there to help everyone. " Philip Hughes.

David's GP and local nursing team have worked with David for some months now to help him to be less anxious about going to hospital, in case an emergency arises. They are concerned that if David became suddenly unwell, it would be very difficult to get him to hospital. Their preparation includes helping him get used to having observations taken such as getting his blood pressure checked or blood tests, by loaning a blood pressure monitor. David's care team have printed pictures of his local hospital, the inside of an ambulance and have developed social stories to explain what will happen if David goes to hospital. They have sought to improve David's understanding of emergency health needs and risk of death by using pictures.

Usually someone will know when a person is likely to refuse to go to hospital. Understanding the reasons behind the refusal should inform the emergency plan. Reasons can include previous negative experiences such as being in large buildings where they have experienced fear and trauma. For patients for whom assessments are finely balanced or complex, it is even more important to have the capacity assessment clearly recorded to complement the plan. If another professional deviates from the capacity assessment or care plan, consultation with the people involved in developing that plan and capacity assessment, and clear recorded reasoning, is required.

The person might need to have someone they know to go with them to hospital. This might be part of their reasonable adjustments and could be recorded in their reasonable adjustments digital flag on their clinical records, be recorded in their health and care passport and feature in their day-to-day care plan. There will be occasions when a support worker or a family member may not be available—in the middle of the night, for example. A plan must be created to review how a care provider will respond in an emergency, where a person needs to be supported into hospital. This should include consideration for support at the hospital and at the point of hospital discharge.

It is usual and best practice for the paramedics to call ahead and advise the hospital of a particular patient's needs, e.g. finding a quiet space for them to be taken to rather than the general A&E reception waiting area.

The reasonable adjustments digital flag can be used to indicate on the patients' clinical records which will be accessible by the ambulance service, any reasonable adjustments that are needed, so that if an emergency occurs and the person needs to be conveyed to hospital, these adjustments can be met.

The emergency plan needs to consider as many scenarios as possible so that paramedics do not refuse to take someone to hospital citing, for example, the lack of a support worker available to attend with the person.

Emergency plans may also contain arrangements that are highly restrictive and may require the authorisation of the Court of Protection, where there is time and planning. The Court of Protection is a court in England and Wales that can make decisions on behalf of people who cannot make their own decisions because of something in their mind or brain, for example dementia, autism, or a brain injury. The person who lacks capacity is known as “P” in the proceedings. If you are unsure about whether a decision or care plan needs to be taken to the Court of Protection, please seek legal advice from your organisation’s legal services. (See useful resources on p.22 about the Court of Protection.)

The best way to prepare for a situation where a person may become unable to make a particular decision at a particular time, is to look at a Lasting Power of Attorney for health and welfare, and for when a person has become unable to make the relevant decision, Deputyship – **find more information here** (**https://www.gov.uk/government/organisations/office-of-the-public-guardian**). This ensures a person is able to choose a person, or have a person they trust, to make certain decisions on their behalf.

Implementing the emergency plan and making best interests decisions

One night David wakes up and starts talking loudly. The overnight care team consists of one sleeping member of staff and one waking. The waking staff member goes to see David and upon touching his forehead notices he is hot. She also notices he is biting his hand, something he has not done for some time and usually indicates he is distressed in some way.

This staff member contacts the out-of-hours GP, who advises that they make an appointment for the morning and to contact them if David becomes worse.

David starts to pace his room and talk even more loudly. The staff member notices that he is hunching more than usual. She attempts to look at him, but because he will not sit down, she decides to call an ambulance.

The ambulance team arrives and asks the member of staff whether it would be okay for David if they enter his room. The staff member contacts David’s mum on the phone first so that she can talk to David and advises the ambulance team that she will go with one of them into his room. While David’s mum is talking to David, he starts to sit down but remains agitated. The paramedic is able to take David’s temperature and notices a fever, but they can’t convince him to give them his finger for an oxygen saturation monitor.

The ambulance crew speak to the staff member and decide that David is unable to consent to being taken to hospital in the ambulance but that it is in his best interests to go to hospital for medical assessment and treatment. The ambulance crew advise that a member of staff would need to come with him.

The staff member contacts her manager and advises of the situation. The manager agrees to come to the house, and the staff member wakes her colleague and explains the situation. This means that one person can go with David in the ambulance and the wellbeing of the other residents continues to be supported by the manager and remaining staff member.

David continues to pace. When trying to persuade David to get in the ambulance, the paramedics agree that they will be unable to take him in an ambulance without a sedative. The paramedics administer the minimum dose that has been prescribed by the GP as part of the emergency plan and is held at the care home for emergency use.

The paramedics then manage to support David out of the house towards the ambulance. At times, David refuses to move forwards. The paramedics consult with the care staff about the level of restraint that is necessary and proportionate to encourage David to get into the ambulance. They make a best interests decision to hold his hands and put their other hands on his back to move him forward as gently as possible.

Reasonable adjustments

David's family live 70 miles away. They have explained to his care service that talking to David on the phone sometimes helps him feel calmer and have requested that they be kept on the phone if he needs to go to hospital.

Comments

It is a legal requirement under the Equality Act 2010 to make reasonable adjustments to ensure that a disabled person can access health and care services. Calling David's parents is an appropriate reasonable adjustment that can be made and should feature in the Emergency Care Plan. Other reasonable adjustments may include having a familiar object or comforter with them, playing music or singing a familiar song. David likes rock music, so playing a favourite track may help him keep calm if the situation allows.

Preparing for such an emergency is critical and may involve layers of liaising and communication. Your local learning disability nurses are essential in this type of scenario. They could support with desensitisation exercises and help to unpick the person's worries with support staff and family. A good example of best practice is when a mini-MDT is convened as part of preparation for emergency hospital admissions. This may include explaining what might be expected, such as the use of sirens or the beeps or whirring noises made by equipment. Pre-planning for reasonable adjustments includes using videos, pictures and photographs. For example, it would be helpful to show patients with learning disability **this video** (**https://www.youtube.com/watch?v=F2PtqwzZfek**) which explains what can be expected when they are admitted to hospital.

If possible, people should be supported to visit the hospital and the areas where they may need to go to, in preparation for an emergency visit.

The Stop People Dying Too Young Group said: "Don't just rely on the sedative, start desensitisation early and keep going with it".

They suggested:

- Using **Books Beyond Words** to create a personalised book for David about visiting hospital which includes photos of the actual building, people and rooms he would encounter; taking any other objects that would comfort and support David, like Leeds United merchandise, fidget toys, noise cancelling headphones, an iPad, etc.; visiting places increasingly close to the hospital without actually going to the hospital; going to the hospital café without having any medical appointments; visiting the ambulance station to see the ambulances without having to go in one; using talking therapies depending on his verbal ability.
- Using what David responds to in other situations in terms of positive reinforcement – one family carer explained that she spoke to her son's doctors and told them how to greet him, how to praise him, what he responds well to, how much eye contact to use, etc. She said, "people need to enter David's world and see it through his eyes".
- Asking, is this part of a bigger picture of anxiety? If so, how is that being treated?
- Identifying what the main issue is. Is it the ambulance, the medical setting, or the

medical staff? Pinpoint the trigger and work on that.

- Understanding David’s triggers – is it sensory? What about numbers of people (quite often lots of students will accompany a consultant – work this out in advance if this should not happen)? Is it what people are wearing?
- How much time have the hospital staff got to spend with David? How committed are they to getting to know him? How much understanding of learning disability and autism have they got?

When David is admitted to hospital he is found to have an inflamed appendix and he undergoes emergency surgery. If he had been left at home his appendix would have burst and he would have been at high risk of death.

National messages and further discussion

Using restraint in an emergency situation

During the development of this guide, we identified a significant issue that can only be addressed with changes to national policy and guidance.

It is clear that restraint should always be considered as a last resort. But it is also clear that there are situations where those involved reasonably believe that the person's condition is potentially life threatening and they require emergency admission, to which they cannot consent and which they are objecting.

If it is decided that it is in their best interests to be taken but they require physical restraint to go into and remain in the ambulance – who should deliver the physical restraint where no other person is available, and time is critical?

Before the publication of **Right Care Right Person**, in mental health situations police were at times called to assist when physical restraint was required. Discussions during our roundtables mentioned that ambulance crews are not trained to undertake restraint when a person needs to be taken to hospital for physical treatment and there is no policy or guidance to which they may refer. In addition, the police may refuse to attend for the purpose of securing medical assessment and treatment for physical health reasons (as well as for mental health reasons).

There is also the matter of sedation or chemical restraint. This may be the best solution to use in an emergency. However, it requires a level of supervision usually given by a critical care paramedic which may be a resource challenge in an emergency situation.

Early deaths of black people with a learning disability

A vitally important point, we continue to see premature and avoidable deaths of disabled people with additional protected characteristics present such as race. The most recent **LeDeR report** makes clear that black people with a learning disability are 190% more likely to die earlier when adjusting for other demographics. It is important to start a discussion on whether these groups should be prioritised in medical waiting lists and to receive annual health checks.

Reasonable adjustments digital flag

Health and care staff should record a person's impairments in their digital flag and the reasonable adjustments they require in emergency and other health and care situations, these will be accessible for all health care staff to enable anticipatory reasonable adjustments to be made.

Social care staff should help people to prepare for emergency hospital admissions

This sounds straight forward. But during our roundtables we spoke to a few care providers, who highlighted that if an ambulance is called in the early hours, and the person who needs to attend hospital draws on care and support, ambulance crews will request attendance of a member of staff.

We were informed that care arrangements don’t always cover the ability to send a member of staff to hospital, where there is more than one person to support in the residence. This raises questions about the terms and conditions of 24-hour support and its preparedness for when emergency hospital treatment is required.

Must-dos for getting people to hospital

- MCA sections 5 and 6 refer to situations where a decision needs to be made in an emergency situation and those involved reasonably believe that the person lacks the relevant decision-making capacity. This includes the use of proportionate, short-term restraint if the emergency requires it. Make sure that a discussion has taken place with any existing care team, and where possible, family members or close contacts. Their advice is critical if you have a reasonable belief that the person is unable to make the decision to go to hospital, is refusing to go, and a best interests decision, by the paramedic team is required to take them.
- Ambulance crews should ensure that when they contact A&E, they advise that, because the person they are transporting has been determined as unable to make the relevant decision, a best interests decision has been made. A&E should be advised of any additional intervention required to get the person to hospital owing to anxiety about the hospital setting. The decision-making should be recorded at the earliest opportunity.
- All social care settings that support people should consider how they would be able to respond to a person needing to be supported into hospital, especially where refusal is likely and additional measures need to be taken.
- If short-term restraint is required, familiar staff should be available to assist to ensure the correct approach is used with the least amount of impact on the individual. However, it is acknowledged that not everyone has such support and decisions will need to be made about contingency planning.
- Social care and health teams should support individuals to have a written plan that details how to respond in a medical emergency. This should include the consideration of reasonable adjustments, the steps required to alleviate anxiety and any form of short-term, reasonable and proportionate restraint to convey a person to hospital where all other options have been exhausted. It also needs to be considered whether the intervention is serious enough to warrant authorisation from the Court of Protection.

One-page overview for practitioners

The Mental Capacity Act (MCA) governs all decisions regarding care and treatment for people aged 16 and over who may not be able to make their own decisions. It applies in all settings and situations.

In most situations, we believe that forward planning is possible for a person who is reluctant to be taken to hospital, has usually shown reluctance in other situations, and there are opportunities to work on the reluctance and look at reasonable adjustments.

However, there are situations where forward planning is not possible, the situation appears life threatening for the person, and an urgent decision needs to be made to convey the person to hospital.

There are times when an urgent decision needs to be made to admit a person to hospital for physical treatment and investigation. A paramedic may reasonably believe that the person is unable to make the decision to be taken in the ambulance but no-one has prepared an emergency admission plan or considered reasonable adjustments.

In this situation, a decision needs to be made in the person’s best interests. To this end, carers and professionals should rely on MCA sections 5 and 6. These legal provisions mean that if you have formed a reasonable belief that someone lacks capacity to make a particular decision, you can act in their best interests. You need to speak to others and the person concerned to decide what course of action is in their best interests.

If restraint is required to get the person to hospital, it is possible that it might last for a sufficiently long time that it constitutes a deprivation of liberty. An ambulance journey might possibly constitute a deprivation of liberty, but only if it is a very long journey or with very high levels of physical restraint. **Concern about whether there will be a deprivation of liberty should not prevent the person being taken to hospital if their life is at risk**. In such a situation, the need to preserve life is likely to prevail over any issue about deprivation of liberty.

Always review urgent decisions as soon as possible after the event, reviewing the impact on the person and if any improvements could be made for future situations.

Get me to hospital – do not delay if my life is at risk

Getting to hospital – my rights

For an easy read guide about the Mental Capacity Act and associated rights please see: ‘**About the Mental Capacity Act and our rights**’.

(**https://safeguardingadults.co.uk/wp-content/uploads/2024/09/FINAL_Easy-Read_About-the-Mental-Capacity-Act-2024.pdf**)

The Mental Capacity Act supports people to make decisions for themselves whenever they can.

In this guide, we talk about when a person has been assessed as unable to make a decision about going to hospital in an ambulance, and a paramedic needs to make a decision to get the person to hospital, in their best interests.

To decide if it is in the person’s best interests, the paramedic must speak to the person and find out what they think and feel about the decision, and, if possible, speak to their family or friends.

A person might say that they do not want to go to hospital, but a paramedic may reasonably believe the person may be very unwell and may even die if they do not go.

We want to make sure that people plan ahead for an emergency and let people know how to support them to feel less scared when they need to go to hospital.

If someone takes a person to hospital even when they are saying no, because they believe the person is not able to make that decision, there are ways a person can make sure their views and wishes, and even rights are considered.

We say if a person is assessed as not able to make the decision that they should be supported by an advocate. This could be a family member or friend, or someone who works and is paid as an advocate. They will be called an Independent Mental Capacity Advocate for MCA decisions. Their job is to help people make sure their views and wishes are made clear to anyone making a decision on the person’s behalf.

If an advocate is not available because, for example, it is the middle of the night, the person can ask for one as soon as they are available.

We also say that people should have a meeting when they feel well enough, to talk about what happened and if the right actions were taken. Their advocate should be invited to that meeting.

Please see the **British Institute of Human Rights** for more information on human rights, including:

- **Easy read hub** for general easy read information on human rights
- **Your easy read guide to the Human Rights Act** (**https://www.bihr.org.uk/media/blajmbdx/easyreadhra.pdf**)

Useful resources

Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust, **Your guide to emergency health care plans: Easy read** (**https://www.cntw.nhs.uk/wp-content/uploads/2022/03/emergency-health-care-plan-FINAL-EASY-READ-PIL.pdf**)

Rotherham, Doncaster and South Humber NHS Foundation Trust, **Venepuncture with reducing restrictive interventions (RRI) for people who lack capacity to consent procedure** (**https://www.rdash.nhs.uk/policies/venepuncture-with-reducing-restrictive-interventions-rri-for-people-who-lack-capacity-to-consent-procedure/**)

Reasonable adjustments digital flag

The Learning Disability Network, **Reasonable adjustment flag**, (**https://necldnetwork.co.uk/work-programmes/digital/reasonable-adjustment-flag/#:~:text=The%20Reasonable%20Adjustment%20Digital%20Flag,Board)%20reasonable%20adjustments%20flag%20project**)

The Learning Disability Network, **Reasonable adjustment digital flag project report** (**https://necldnetwork.co.uk/wp-content/uploads/2023/12/Report-for-Tasks-1-and-2-The-Reasonable-Adjustment-Flag.pdf**)

The Learning Disability Network, **Reasonable adjustment campaign** (**https://necldnetwork.co.uk/work-programmes/reasonableadjustments/**)

Capacity assessments

39 Essex Chambers, **Mental Capacity Act guidance notes** (**https://www.39essex.com/information-hub/mental-capacity-resource-centre/mental-capacity-resources/mental-capacity-guidance**)

NHS, London Region MCA /DoLS resource pack (Powerpoint presentation)

Best interests decisions

SCIE, **MCA: Best interests principle** (**https://www.scie.org.uk/mca/practice/best-interests/**)

The Court of Protection, **A basic guide to the Court of Protection** (**https://courtofprotectionhandbook.com/wp-content/uploads/2020/07/a-basic-guide-to-the-court-of-protection-july-2020-3.pdf**)

Deprivation of Liberty Safeguards (DoLS)

The Law Society, **Understanding when someone is deprived of their liberty** (**https://www.lawsociety.org.uk/topics/private-client/deprivation-of-liberty-safeguards-a-practical-guide**)

References

LeDeR, **Learning from lives and deaths: People with a learning disability and autistic people** (**https://www.kcl.ac.uk/research/leder**) (annual report, 2022)

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