



THE LANTERN COMMUNITY  
*"living, learning and working together"*

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## THE LANTERN COMMUNITY GUIDANCE ON CONSENT FOR CARE AND TREATMENT

Prepared by The Lantern Management Group and ratified by The Lantern Community Trustee Board

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### GLOSSARY OF TERMS:

**Lantern Community:** The organisation responsible for providing the care and support services

**Companion:** Beneficiary of the charity; adult at risk who is receiving the care and support services

**Co-worker:** A person who works on a voluntary basis for Lantern Community which provides personal care and support services for adults with learning disabilities or mental health problems.

**Employee:** A person who works for the Lantern Community which provides personal care and support services for adults with learning disabilities or mental health problems.

This policy needs to be read in accordance with:

- The Lantern Community Policy on Mental Capacity Act
- The Lantern Community Safeguarding Adult Policy and Procedure
- The Lantern Community Policy on Care Needs Assessment and Care Planning

## **GENERAL POINTS ON CONSENT**

For a companion's consent to be valid, the companion must be:

- capable of taking that particular decision ('competent')
- acting voluntarily (not under pressure or duress from anyone)
- provided with enough information to enable them to make the decision.

Seeking consent for care and treatment is an essential part of a respectful relationship with the companions and should usually be seen as a *process*, not a one-off event.

When a companion's consent to treatment or care is sought, co-worker or employee should make sure they have the time and support they need to make their decision, unless the urgency of their condition prevents this. Companions who have given consent to a particular intervention are entitled to change their minds and withdraw their consent at any point, if they have the capacity (are 'competent') to do so. Similarly, they can change their minds and consent to an intervention which they have earlier refused. It is important to let the companion know this, so that they feel able to tell you if they change their mind.

Where a companion objects and appears to withdraw consent during treatment or care, it is good practice to stop the procedure, if possible, and to establish the companion's concerns. Sometimes, an apparent objection may reflect pain or distress, rather than withdrawal of consent, and appropriate reassurance may enable you to continue with the procedure. If stopping the procedure at that point would genuinely put the companion's life at risk, you may be entitled to continue until the risk no longer applies.

Adults with the capacity to take a particular decision are entitled to refuse the treatment and care being offered, even if this will clearly be detrimental to their health.

The only exception to this rule is where treatment is being provided for mental disorder, under the terms of mental health legislation (in which case more specialist guidance should be consulted).

Legally, it makes no difference whether companions sign a form to indicate their consent, or whether they give consent orally or even non-verbally (for example by holding out an arm for blood pressure to be taken). A consent form is only a record, not proof that genuine consent has been given. It is good practice to seek written consent if treatment is complex, or involves significant risks or side-effects. If the person has the capacity to consent to treatment for which written consent is usual but cannot write or is physically unable to sign a form, a record that the person has given oral or non-verbal consent should be made in their notes or on the consent form.

## **DOES THE PERSON HAVE CAPACITY?**

Adults are always presumed to be capable of taking healthcare decisions, unless the opposite has been demonstrated. Where any doubt exists, a senior supporter should assess the capacity of the person to make the decision in question, drawing on the assistance of specialist colleagues such as learning disability teams and speech and language therapists as necessary. This assessment and the conclusions drawn from it should be recorded in the companion's notes or, where appropriate, in a form for adults who are unable to consent.

For companions to have the capacity to take a particular decision, they must be able to

- comprehend and retain information material to the decision, especially as to the consequences of having or not having the intervention in question, and
- use and weigh this information in the decision–making process.

It is very easy for an assessment of capacity to be affected by organisational factors such as pressure of time, or by the attitude of the person carrying out the assessment. It is supporters' professional responsibility to ensure that they make as objective a judgement as they can, based on the principle that the companion should be assisted to make their own decision if at all possible. It is essential that the information available for companions is appropriate and accessible.

Methods of assessing comprehension and ability to use information to make a choice include:

- exploring the companion's ability to paraphrase what has been said (repeating and rewording explanations as necessary);
- exploring whether the companion is able to compare alternatives, or to express any thoughts on possible consequences other than those which you have disclosed;
- exploring whether the companion applies the information to his or her own case.

Companions will often have support from people close to them (family members, carers or friends) or from independent "supporters" or advocates, who can help them understand the issues and come to their own decisions. Where appropriate, colleagues from local learning disability community teams will also be able to act as 'health facilitators' on behalf of the companion.

Some companions may have capacity to consent to some interventions but not to others. People with a mild to moderate learning disability, for example, would probably have capacity to make many straightforward decisions about their own care (such as deciding whether to have an operation to correct a hernia), but some might lack capacity to take very complex decisions. It should *never* be assumed that people can take no decisions for themselves, just because they have been unable to take a particular decision in the past. Occasionally an individual might temporarily lack capacity to take a particular decision because of an extreme phobia (for example, an overpowering fear of needles); again supporter should never assume that the individual lacks capacity to make any other decisions.

Capacity should *not* be confused with the subjective assessment of the reasonableness of the companion's decision. People are entitled to make a decision based on their own religious belief or value system, even if that decision is perceived by others to be irrational, as long as they understand what is entailed in their decision. For example, a person might refuse an operation which professionals believe is in their best interests because they do not want to take the risk, even if the risks in fact are very low. If a decision seems irrational, discuss it with the companion and his/her circle of support, and find out the reasons for the refusal. In some cases, further information and discussion may mean the companion would want the treatment to go ahead, perhaps in a slightly different form. However, supporter must never try to coerce the companion into changing their decision. Seeking consent is about helping the person make their own, informed, choice, and different people will come to different decisions.

In practice, people also need to be able to communicate their decisions. Employees or co-workers should take all steps which are reasonable in the circumstances to help communication between himself and the companion, using interpreters or communication aids as appropriate. If supporters and the person are having difficulties understanding each other, those close to the companion may well be able to help, as may specialist colleagues such as speech and language therapists.

## **WHAT INFORMATION DO PEOPLE NEED?**

Companions clearly need enough information before they can decide whether to consent to, or refuse, treatment. In particular, they need information about:

- the benefits and the risks of the proposed treatment
- what the treatment will involve
- what the implications of not having the treatment are
- what alternatives may be available
- what the practical effects on their lives of having, or not having, the treatment will be.

It is essential that this information is provided in a form that the particular companion can understand. This may involve using pictures, or explaining what is involved in simple terms and short sentences and being willing to repeat or reword explanations. Communication aids such as boards where people can indicate 'yes' or 'no' may also be helpful. Supporter should also always check to make sure that the person has understood. If the companion uses a sign language such as Makaton, then again an interpreter will be needed.

The manner in which information is presented is also important. Supporter should ensure that information is provided in a respectful way, for example by finding an appropriate, private place to discuss confidential matters.

## **IS THE COMPANION'S DECISION MADE VOLUNTARILY?**

It is very important to ensure that the companion's decision is truly their own. Clearly, both employees/co-workers and people close to the person have a role to play in discussing the options, but supporter should take care that companions do not feel forced into making decisions they are not happy with because of pressure from others, or are simply agreeing out of a desire to comply with authority.

## **GENERAL POINTS**

Even where information is presented as simply and clearly as possible, some companions will not be capable of taking some decisions. If a person is *not* capable of giving or refusing consent, it is still possible for employees/co-workers lawfully to provide treatment and care. However, this treatment or care *must* be in the person's "best interests".

No-one (not even the person's parents, or others close to them) can give consent on behalf of adults who are not capable of giving consent for themselves. However, those close to the incapacitated person should always be involved in decision-making, unless the person makes clear that they don't want particular individuals to be involved. Although, legally, the health professional responsible for

the person's care is responsible for deciding whether or not particular treatment is in that person's best interests, ideally decisions will reflect an agreement between professional carers (doctors, nurses, dentists etc) and the individual's family and friends.

## **BEST INTEREST**

The companions' "best interests" are not limited to what would benefit them *medically*. Other factors, such as their general well-being, their relationships with those close to them, and their spiritual and religious welfare, should all be taken into account. Moreover, people who lack capacity to consent to or refuse a particular treatment option may still express willingness or unwillingness to co-operate with what is being offered. Such preferences should always be taken into account when deciding whether the proposed care or treatment is genuinely in the companion's best interests. For example, if, despite all reassurance, a companion becomes very distressed by a particular investigatory procedure, this will be an important factor to bear in mind when deciding if the procedure is really essential.

The only interests which supporter should take into account when deciding if particular treatment is appropriate are the *companion's* best interests. It is not lawful to balance these interests against the interests of their family, the interests of health professionals, or the interests of other people living with the companion. However, these interests will often be inter-linked: for example the effect of a treatment decision on family relations should be taken into account as part of the companion's "best interests", where family support is important to the person with learning disabilities.

Ideally, decisions should be made which both those close to the companion and the healthcare team agree are in the companion's best interests. If it proves impossible to reach such agreement over significant decisions, the courts can be asked to determine what is in the companion's best interests. The courts have stated that certain procedures (including sterilisation for contraceptive purposes and donation of regenerative tissue such as bone marrow) should never be carried out without being first referred to a court. It is very unlikely that it would ever be in the best interests of a person lacking capacity to donate a solid organ, but were this to be considered it should also be referred to a court.

Family members cannot require clinicians to provide a particular treatment if the health professionals involved do not believe that it is clinically appropriate, but as part of a good relationship with those close to the person, professionals should explain why they believe the treatment is inappropriate. Where possible, a second opinion should be offered. It should be never assumed that particular treatments are inappropriate just because the patient has a learning disability. This is discriminatory and unlawful.

Where a decision to provide treatment is taken on the basis that this is in the companion's best interests, the standard consent form should not be completed. Instead, staff should use the Best Interests Assessment, a written record (either in the person's notes or on a form for adults who are unable to consent) of the reasons for the decision and the involvement of those close to the person. Any disagreement between the clinical team and those close to the person should also be recorded in that document.