

The Making Decisions Alliance brings together a wide range of organisations and groups, working with people who may, for range of different reasons, have difficulty in making or communicating decisions.

### **Why the Mental Incapacity Bill is not about euthanasia**

The current law does not provide sufficient protection for people who may have difficulty making decisions, for people who lack capacity or those who look after them. The law is confusing and fragmented. The range of people who are let down by the current law is considerable. They include people with learning disabilities, people with autism, people with mental health problems and those who lose the ability to make decisions at later life.

The Making Decisions Alliance does not think that the Bill contains any provisions to change the law on euthanasia. We feel that statements issued by organisations that suggest that there is a link are wholly misleading and misrepresent the purpose of the mental incapacity bill, which is to empower the rights of people and give greater protection when needed.

Euthanasia and physician assisted suicide are both illegal in the UK and are likely to remain so. The Making Decisions Alliance is not supporting any changes in law that would make euthanasia or physician assisted suicide more likely. The ban on euthanasia and physician assisted suicide is designed to protect the most vulnerable members of society from abuse and the Mental Incapacity legislation seeks to strengthen rather than undermine this level of protection for those who have difficulty making decisions.

The Making Decisions Alliance has clear policy opposing euthanasia. It has opposed proposals for changing the law to allow interventions, whose sole purpose is to end life. It also accepts that, legally and ethically, patients can refuse life-prolonging treatment and that interventions designed to keep patients comfortable and pain-free may reduce their lifespan.

The Making Decisions Alliance's support for the introduction of mental incapacity legislation is due to a desire to improve the quality of life and to protect all people who have difficulty making or communicating decisions. Indeed changes recommended by the Alliance could be seen as strengthening the possibility for the individual to assert their right to a good quality life.

An individual will be able to plan for the future by granting a lasting power of attorney to a person of their choice, which is exercised in the event of future incapacity. In addition, an individual will be able to make an advance statement setting out which medical treatment that person would or would not

be prepared to accept if he or she should subsequently lose the capacity to decide for himself or herself. The MDA supports the proposals in the draft Bill that allows an individual to appoint another person to refuse consent to life-sustaining treatment where it is specifically mentioned in the lasting power of attorney, and to give or refuse consent to treatment to which an existing advance statement relates. We believe that these provisions in the Bill achieve the right balance between promoting maximum autonomy for an individual and providing sufficient safeguards for that person.

An advance statement is a declaration that an adult gives about the care and support they would wish to receive. One of the types of statement that can be given is an advance directive, which contains an adult's instructions as to which medical treatment that person would or would not be prepared to accept if he or she should subsequently lose the capacity to decide for herself. Advance directives are simply a method whereby a person can exercise his or her right to reject medical treatment and at present is already legally binding on professionals, as established through case law.

Advance directives are sometimes concerned with the refusal of life sustaining procedure in the event of terminal illness. They have nothing to do with euthanasia or suicide. They cannot authorise a doctor to do anything which is illegal or which a person with capacity could not request a doctor to do. Nor can an advance statement request a treatment, which is clinically inappropriate.

The Making Decisions Alliance strongly supports advance statements, as well as advance decisions, being included within the bill. This would provide an opportunity for those who wish to make a positive statement regarding their wish to receive life-sustaining treatment. This could therefore act, as a powerful safeguard and form of protection for those who do not wish for medical treatment to be withheld or withdrawn under any circumstances. The Alliance believes that wherever possible the individual should be involved in such choices and we believe the mental incapacity legislation will strengthen that right.

Furthermore the Making Decisions Alliance wish to see the power to make a decision about withholding or withdrawing life-sustaining treatment removed from the Court of Protection appointed deputies and believe it would not be reasonable to make it under the powers of the General Authority to Act. As these deputies will not have been appointed by the individual, there are consequentially less safeguards to ensure they will represent the individual's wishes in such situations. We are, therefore, concerned that it would undermine the level of protection offered to the individual around end of life issues.

Under the draft Mental Incapacity Bill, professionals will be legally required to determine the best interests of a person who lacks capacity, to find out everything possible about their wishes and feelings and to take all reasonable steps to involve them in decisions made about them. This adds considerable safeguards to all decisions made on the behalf of any individual who is unable

to make their own decisions. Planning and taking decisions around end of life issues are deeply personal. The proposed legislation will allow a person's views and wishes to guide others if they are unable to make the decision themselves. The Making Decisions Alliance strongly supports this as it will prevent health and social care professionals from applying different standards based on their own assumptions about whether someone has no, or a low, quality of life.

Health and social care professionals should never make negative assumptions about the quality of life of an individual when considering what is in that patient's best interests. Considerations of 'quality of life' are only relevant in the context of the gravity of illness and do not concern the degree or nature of a person's disability.

### **Withdrawing and withholding medical treatment:**

Every person has the right, no matter how ill or close to death, to comfort and freedom from pain, a high quality of medical and nursing care with proper treatment for their position. The Alliance supports the GMC's guidelines on Withholding and Withdrawing Life-prolonging Treatments: Good Practice in Decision-making, which emphasises that each case is taken on an individual basis, and that patients should wherever possible, be involved in such decisions.

Artificial nutrition and hydration (for example, tube feeding) is a form of medical treatment, and is distinct from good practice in the provision of nutrition and hydration (such as moistening lips). The individual should be given the opportunity to oppose the continuation of invasive treatments that have no clinical benefit to themselves that may cause them unnecessary suffering.

### **Conclusion**

The Making Decisions Alliance supports the proposed mental incapacity legislation, which would add to protection for people who lack capacity and help ensure that decisions are taken in their best interests, taking account of their preferences. The legislation will not add to the likelihood of euthanasia or physician-assisted suicide. The Making Decisions Alliance does not believe that this is either the intention or a consequence of the proposed legislation. Furthermore, the MDA is concerned that the erroneous link made between euthanasia and legislation on mental incapacity may prevent the Bill from becoming law, to the detriment of millions of people who have difficulty making or communicating decisions.