

Respecting the autonomy of the living and dying

Abstract

Purpose

To inform those who are supporting persons who are dying and are responsible for planning, commissioning or delivering palliative care about the need to support and maximise the decision-making ability and choices of persons with advanced dementia or severe frailty .

Approach

This article will consider the legal and human rights principles applicable to Scotland, and indeed to other jurisdictions, which govern decisions about care and treatment of persons with and without capacity and the application of these principles to palliative care situations.

Implications

It is a well-established legal and human rights principle that the decisions of a person with capacity must be respected, including decisions about palliative care and treatment at the end of life. Moreover, recent developments in international human rights law reinforce the message that this principle applies equally to all. Applying this principle to persons with advanced dementia or severe frailty therefore requires skilled assessment and supported decision making in order to optimise capacity and respect autonomy.

Value

An awareness of the underpinning legal and human rights framework which underpins decisions made that concern persons with advance dementia or severe frailty and their palliative care respects and enhances their choices and dignity.

1. Introduction

Mental capacity – the ability to make decisions, to have wishes and feelings about things – is something we all possess to a greater or lesser degree throughout our entire lives. Legal capacity, on the other hand, is the ability to have our wishes and feelings, or will and references, respected and put into effect. This might be, for example, about where and how we live, who we associate and enter into relationships or contracts with or care and treatment for physical or mental health conditions, including in palliative care situations. Being able to freely exercise our legal capacity is integral to individual autonomy.

Whilst normally our wishes and feelings must be given effect there are situations where these might have to be legitimately restricted, for instance where there is a risk to public health and safety or to prevent or punish the commission of criminal offences. Age, as in the case of young children, and conditions impacting on one's understanding and inability to make decisions which are not harmful to oneself or others have also been considered to constitute valid reasons to limit the exercise of our legal capacity.¹ Of course, adherence to the principles of the rule of law, human rights and ethics require that such restrictions must be

¹ Age of Legal Capacity (Scotland) Act 1991; Adults with Incapacity (Scotland) Act 2000; Mental Health (Care and Treatment) (Scotland) Act 2003.

subject to strict measures to prevent these being disproportionately and arbitrarily applied. Human rights treaties, such as the European Convention on Human Rights (ECHR) and United Convention on the Rights of Persons with Disabilities (UNCRPD), emphasise, for example, the need to respect and safeguard individual autonomy wherever possible. Supporting the ability to make choices is also implied here and the UNCRPD goes even further in that it explicitly directs that states must ensure access to appropriate support to assist persons with disabilities to overcome decision-making difficulties.² Being able to exercise one's legal capacity, as an essential component of individual choice, is as relevant to the dying as to anyone else. It is therefore important that those who are supporting persons who are dying and are responsible for planning, commissioning or delivering palliative care carefully understand the full implications of these requirements.

This article will consider how the legal and human rights framework in Scotland relating to adult capacity can be applied, in conjunction with any professional guidance, in the context of palliative and end of life care. It is important that such framework is applied at all times, including during times of national crisis such as the COVID-19 pandemic. However, whilst the article will be referring mainly to Scotland the human rights implications may also be applicable to other jurisdictions.

2. Legal frameworks, capacity, end of life and palliative care

Valid consent to, refusal of and directing one's care and treatment requires both mental capacity and legal capacity. It is a well-established legal principle that a person with capacity's refusal of treatment for a physical health condition must be respected.³ Nor should the presence of a mental health problem or learning disability automatically lead to an assumption that a person lacks capacity to refuse such treatment.⁴ These principles also apply to decisions concerning end of life and palliative care.

Where a person is experiencing capacity challenges and welfare, care and treatment decisions must be made then a number of questions need to be asked. Such questions include whether the person has granted a welfare power of attorney or welfare guardianship (or intervention) order, and whether these contain powers allowing the attorney, guardian or person empowered to implement the intervention order to make decisions in these circumstances. Where medical treatment to safeguard or promote the individual's physical or mental health is required then it may be possible for a doctor or health professional⁵ to be authorised to administer this under section 47 of the Adults with Incapacity (Scotland) Act 2000 (the AWIA). However, the consent of any appointed welfare attorney or guardian to the treatment should be sought and where there is an application for an intervention or guardianship order is pending only emergency treatment may be administered.

It is important that anyone seeking to act under section 47 certificate, a power of attorney or intervention or guardianship order must apply the AWIA underlying principles. These are designed to ensure that the ability of the adult to make decisions about their life, and thus

² Article 12 UNCRPD.

³ Re T (Adult: Refusal of Treatment) [1993] Fam 95.

⁴ Re C (Adult: Refusal of Treatment) [1994] 1 All ER 819.

⁵ Currently a dentist, optician or registered nurse.

autonomy, is preserved as much as it is possible and that even where the adult is deemed to lack capacity that their wishes and feelings are still taken into account.

Before any measures authorised under the AWIA are decided or taken the adult must be 'incapable', meaning that they are incapable of acting or making decisions or communicating decisions or understanding decisions or retaining the memory of decisions as a result of either mental disorder or an inability to communicate because of physical disability (unless this is simply owing to issues with communication which can be rectified by human or mechanical assistance). The care or treatment must also be capable of achieving a benefit for the adult not otherwise attainable and be the least restrictive alternative. Crucially, account must also be taken of the present and past ascertainable wishes and feelings of the adult as well as the views of the nearest relative, named person, primary carer, guardian, attorney, anyone the court decides to consult or who is otherwise responsible for effecting the intervention. Moreover, signifying that capacity may fluctuate and, with help, improve, a duty is placed on those responsible for implementing measures authorised or regulated by the Act to encourage the adult to make decisions about their personal welfare and other matters insofar as this is reasonable and practicable. The need to reflect the adult's authentic wishes and feelings is also reflected in the AWIA's accompanying Codes of Practice (for example, Scottish Government, 2018) and Law Society for Scotland guidance (Law Society for Scotland, 2013).

At the time of enactment of the AWIA the UK was a party to the ECHR. The Act's underpinning principles were therefore developed with ECHR compliance in mind given that its rights must be reflected in devolved Scottish legislation, followed by public authorities and courts and are enforceable through national courts and tribunals.

3. The European Convention on Human Rights: strengthening respect for capacity and wishes and feelings of the dying

ECHR rights reflect the need to respect autonomy and dignity. In interpreting these rights, the European Court of Human Rights has increasingly adopted an expansive approach towards respect for the exercise of capacity and autonomy in its case law concerning persons with potential capacity challenges. It has emphasised the need for the presumption of capacity, functional capacity assessments (as opposed to blanket assumptions of mental incapacity) and respect for private and family life and that the views of a person who has lost mental capacity must not be discounted.⁶ Nor should a person's status - be it sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status (which includes disability) - be used to justify discrimination in rights enjoyment.

⁶ *Winterwerp v Netherlands* (1979-80) 2 EHRR 387; *Shtukaturov v Russia* (App no 44009/05) (2012) 54 EHRR 27; *Sykora v Czech Republic* (App no 23419/07) (2012) ECHR 1960; *Stanev v Bulgaria* (2012) 55 EHRR 22; *DD v Lithuania* (2012) ECHR 254; *A-MV v Finland* (App no 53251/13) ECtHR, 23 March 2017.

From the ECHR principles impacting on autonomy and the exercise of capacity it might arguably also imply that an adult experiencing decision-making difficulties should be supported to make and communicate end of life decisions and about their palliative care. However, subsequent human rights developments, notably the arrival of the UNCRPD, have made it clear that this is imperative.

4. The United Nations Convention on the Rights of Persons with Disabilities: the non-discrimination and support for decision-making capacity imperatives

The UK became a state party to the UNCRPD in 2009 which obviously followed the enactment of the AWIA. Whilst its rights are not incorporated into the UK, and Scottish, legal framework and are therefore currently unenforceable through national courts and tribunals, they are nevertheless highly influential and cannot be ignored in the implementation of law and practice. Proposed devolved Scottish legislation and policy that is UNCRPD incompatible can be prevented by the UK Government.⁷ The European Court of Human Rights, although to date it has been somewhat equivocal in this respect, must take account of the UNCRPD in its ECHR rulings which, as previously stated, must be followed in the UK. There is also considerable evidence of an appetite on the part of the Scottish Government to give effect to its rights as is reflected in its 2016 UNCRPD Action Plan (Scottish Government, 2016), Mental Health Strategy 2017-2027 (Scottish Government, 2017) and recent and ongoing reviews of adult incapacity and mental health law.

The UNCRPD refers to “Persons with disabilities” as “disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”.⁸ The focus is thus on preventing the ‘disabling’ of persons through practices and attitudes and not on the disability itself. Moreover, the reference to ‘long term’ should not be overstated because the Preamble to the UNCRPD refers to disability as an “evolving concept”. This makes it clear that UNCRPD rights protect those whose physical or mental health vulnerability potentially places them at risk of discrimination (United Nations, undated), persons whose decision-making may be impacted by both long and short term disability, including persons with or without a diagnosed physical or mental disability or health conditions, such as dementia, and who are dying. For the remainder of this article the term ‘persons with disabilities’ should therefore be read to include this broad interpretation.

The UNCRPD builds on and expands the ECHR requirements relating to respecting individual autonomy. It re-emphasises the longstanding international human rights principle that all human rights must be enjoyed equally (in terms of their exercise and limitation) by all persons without discrimination but spells out that disability or related impairment must not justify different rights enjoyment (Committee on the Rights of Persons with Disabilities, 2014, 2018). The concern that led to the creation of the UNCRPD was that the predominantly ‘medical model’ of disability had led to the rights of persons with disabilities being interpreted mainly in terms of defining the perimeters for interventions and allowing for unnecessary and discriminatory restrictions in the name of protection (Arnardóttir and Quinn, 2009; Bartlett, 2013). The treaty therefore seeks to change such perceptions by requiring the proactive supporting of persons with disabilities to exercise rights – such support including

⁷ Sections 35(1)(a) and 58(1) Scotland Act 1998.

⁸ Article 1 UNCRPD.

support for the exercise of legal capacity, reasonable accommodation and universal design⁹ – so that a ‘level playing field’ is achieved in which such rights are equally enjoyed (Minkowitz, 2017; Clough, 2018; Stavert, 2018).

Article 12 UNCRPD restates the equality and non-discrimination message in relation to enjoyment of legal capacity by persons with disabilities. If the views of persons with disability are to be respected in the same way as others then there must be access to appropriate support for the exercise of legal capacity (often referred to as ‘supported decision-making’ or ‘support for decision-making’) to achieve this. The UNCRPD oversight body, the Committee on the Rights of Persons with Disabilities, points out the difference between ‘mental capacity’ and ‘legal capacity’ mentioned above and that persons with disabilities are often denied autonomy when this would not happen in the same situation for those without a disability (Committee on the Rights of Persons with Disabilities, 2014). It notes that difficulties in expressing views or making decisions can result in others discounting the validity of the individual’s will and preferences and substituting what they believe to be in the individual’s ‘best interests’ instead (Committee on the Rights of Persons with Disabilities, 2014). However, the Committee emphasises that challenges surrounding our mental capacity need not prevent us from exercising our legal capacity and can be overcome either (a) through ‘supported decision-making’; or (b) where, despite strenuous efforts to do so, it is impossible to ascertain the individual’s will and preferences then by making a ‘best interpretation’ of what these are (Committee on the Rights of Persons with Disabilities, 2014). This does not mean that the individual’s will and preferences will always prevail – non-discriminatory interventions are permissible on the basis they would apply to everyone in the same circumstances – but the pursuance of equality ‘supported decision-making’ and ‘best interpretations’ of will and preferences is to ensure insofar it is possible that the genuine wishes of the individual is heard in all situations including crises and emergencies.

The UNCRPD and Committee on the Rights of Persons with Disabilities provide a broad idea of what supported decision-making might include (Committee on the Rights of Persons with Disabilities, 2014). Advance planning is mentioned as a form of support, as is advocacy, peer and professional support, clear and appropriately tailored information and technological support (Committee on the Rights of Persons with Disabilities, 2014). The UNCRPD also stipulates that it must be provided free from conflict of interest and undue influence.¹⁰

The Committee’s approach is radical requiring that substitute decision-making arrangements, including guardianship, are abolished and entirely replaced with supported decision-making which is not aligned to diagnosis or impairment assessments so as to ensure equal and non-discriminatory respect for the will and preferences of persons with disabilities (Committee on the Rights of Persons with Disabilities, 2014). However, the system in Scotland currently does make such linkages, albeit underpinned with human rights-based principles designed to prevent disproportionate denial of autonomy. The UNCRPD and supported decision-making must therefore work within the existing framework to maximise such autonomy (Mental Welfare Commission for Scotland, 2016).

⁹ Articles 12 (supported decision-making), 2, 5(3), 14(2), 24(2) (c), 24(5) and 27(1)(i) (reasonable accommodation and 2 and 4(1)(f) CRPD (universal design).

¹⁰ Article 12(4) UNCRPD.

In Scotland and in terms of advance planning, powers of attorney are recognised under the AWIA. Advance statements are only formally recognised in relation to psychiatric care and treatment under the Mental Health (Care and Treatment) (Scotland) Act 2003 and not more widely. In Scotland, there is no case law or legislation relating to advance refusals of treatment for physical conditions. However, it seems likely that the English case law¹¹ and the English Mental Capacity Act 2005 approaches which respect such advance refusals if made whilst the person has capacity will be followed and there is no reason to believe that the person was subject to undue influence or has subsequently changes their mind (Mental Welfare Commission for Scotland, 2016). Other forms of anticipatory care planning – a planning process whereby healthcare professionals work with individuals, carers, and their families to discuss and document their goals and priorities for care (Cumming et al, 2017) and is broadly similar to ‘advance care planning’ used in England (British Medical Journal, 2020) - have no statutory underpinning but are widely used in practice. The right to independent advocacy is again only formally recognised in the Mental Health (Care and Treatment) (Scotland) Act 2003 although it is, subject to resourcing, available and other non-statutory forms of support, particularly in terms of supporting communication are also available (Mental Welfare Commission for Scotland, 2016).

Conclusion

As the law currently stands in Scotland, and indeed in many other jurisdictions, our wishes about our palliative care and treatment as expressed when we have capacity must be respected. There must also be a presumption in favour of respecting our views even after capacity is lost. The existing legal and human rights framework also requires that strenuous efforts must be made to ascertain such wishes and to support the overcoming of decision-making difficulties in order to do this. Evaluation of the effectiveness of different types of support is currently limited but ongoing (Stavert, 2015, 2018; European Network on National Human Rights Institutes and Mental Health Europe, 2020). Moreover, whilst more is required in terms of law reform and practice to ensure the maximisation of individual autonomy in the case of persons with disabilities, including dementia, there is still much that can already be done to achieve this (McKay and Stavert, 2017).

The requirement to ensure that we are not effectively disabled through being discriminated against owing to our particular characteristics (for example, age, mental or physical disability and chronic disease) applies to all situations and circumstances. This has been particularly highlighted in responses to some guidance – such as that contained in ethical and clinical guidance published by Scotland’s Chief Medical Officer – relating to anticipatory care planning in the context of COVID-19 (Stavert and McKay, 2020). The absence of sufficient reference to relevant legal and human rights frameworks in such guidance have the potential to cause those responsible for the care and treatment of certain categories of patients - particularly the older persons, and those with learning disability, mental illness and dementia – to inadvertently make decisions that are discriminatory and in breach of the individual’s human rights (Stavert and McKay, 2020).

It is therefore important that health and care professionals work together and with families to give effect to the rights, will and preferences of persons with long or short-term disabilities

¹¹ See footnotes 3 and 4 (op cit).

such as advanced dementia, delirium or communication and sensory impairments associated with advanced frailty by enabling ‘supported decision making’ that:

- Optimises capacity by overcoming communication barriers and reversible sensory impairments; and
- Encourages proactive expression of wishes through anticipatory care planning or advance care planning conversations; and
- Using, where there is a specific need, independent advocacy.

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