Terminally Ill Adults (End of Life) Second Reading Briefing: Eating Disorders

Introduction

This briefing is prepared by Professor Gareth Owen, Professor Alex Ruck Keene KC (Hon), Professor Katherine Sleeman and Dr Lucy Stephenson, all members of the Complex Life and Death Decisions Group (CLADD). CLADD is a King's College London based group with expertise in psychiatry, palliative care, bioethics, public policy and law. We are neutral as to whether assisted dying / assisted suicide should be made law. We are committed to the principle that it is for Parliament to decide. We are equally committed, however, to the principle that any law that is passed must function as a workable framework which protects the interests of patients, professionals and wider society.

In our broader briefing, we set out why the Terminally Ill Adults (End of Life) Bill ('the TIA Bill') as it stands is not good law. We have prepared a version of the Bill which remedies the key problems that we identify in that briefing. This briefing looks in more detail at the issue of eating disorders. It provides an outline sketch of the reasons eating disorders have become prominent in the debate around the Bill and resultant points of tension for the Bill in its current form.

Policy intent and the prominence of eating disorders in the debate

Kim Leadbeater MP is clear that she does not wish to include those with anorexia nervosa within the scope of the Bill. Yet transcripts of the debates on the Bill in the House of Commons contain over 250 references to 'anorexia' or 'eating disorders'. This count gives a sense of the perhaps surprising prominence of what is generally understood to be a mental illness in a debate about a Bill designed for people with physical, terminal illnesses. We set out below reasons for this prominence, and draw awareness to sections of the Bill which will need more detailed attention to manage the issues eating disorders raise.

What is anorexia nervosa?

Particular attention has been paid to anorexia nervosa (hereafter anorexia). This is the most lethal psychiatric disorder because of the possibility of severe nutritional compromise and resultant death (1). Key symptoms are significant nutritional compromise (BMI under 18.5) driven by restriction of food intake due to concerns about body weight and shape. Anorexia affects around 4% of females and 0.3% males. The onset is usually during adolescence and emerging adulthood but more recently has increased in people under 15 (2). For those diagnosed with anorexia recovery rates are around 50-80% but a subset of around 20% go on to develop longstanding illness (3) (4) (5). Recovery from anorexia takes on average 7-10 years (1) and is still possible even after many years of illness.

Defining terminal illness and the challenges of eating disorders

In clause 2 the Bill sets out a definition of terminal illness. This appears to be a common-sense definition if one has in mind e.g. a person experiencing a life-limiting cancer. However, it is important to understand that eating disorders might also fit within these definitions. By breaking down the definition of terminal illness in the Bill as it stands (in clause 1), we can see how eating disorders pose a challenge at several stages:

Clause 2 (1)

For the purposes of this Act, a person is terminally ill if—

(a) the person has an inevitably progressive illness or disease which cannot be reversed by treatment, and

Within the field of eating disorders there has been intense debate about the concept of 'terminal anorexia' (6). This term was proposed to describe those with advanced illness who do not want further treatment, where compulsory treatment is not thought to be appropriate and where death is expected as the natural outcome of no nutritional intake. From this perspective, the anorexia 'could not be reversed' by treatment. The concept of 'terminal anorexia' has proved highly controversial and has largely been rejected by the eating disorder community. The term has now been retracted by the original authors who proposed it. Nonetheless, instances persist in clinical practice and in the Court of Protection where the futility of persistent, long term, coercive treatment aimed at nutritional restoration is acknowledged and instead a holistic, supportive approach is taken (1) (3).

In these circumstances, we suggest that it cannot be ruled out that an assessing professional could reasonably conclude that a person with anorexia would – but for the mental disorder exception in clause 2(4) – satisfy this limb of the terminal illness criterion. This, in turn, places severe pressure on the mental disorder exception, discussed below.

Clause 2 (1)

(b) the person's death in consequence of that illness or disease can reasonably be expected within six months.

It is a simple truth that without hydration or nutritional intake death is certain within a far shorter period than 6 months. For those with severe anorexia there is a high risk of death due to malnutrition unless there is intervention and coercion may be needed to achieve this e.g. compulsory feeding via nasogastric tube. If some degree of nutritional restoration is achieved physical recovery is highly likely to be possible (7). Determining prognosis in a more holistic sense i.e. physical and psychological and the likelihood that a person would be able to independently maintain a healthy weight is more complex.

Clause 2(2)

A person who would not otherwise meet the requirements of subsection (1) shall not be considered to meet those requirements solely as a result of voluntarily stopping eating or drinking.

This clause addresses instances where individuals may attempt to render themselves 'terminal' according to the definitions in (a) and (b) by refusing oral intake. This would mean their death is inevitable in less than 6 months. In other jurisdictions the voluntary stopping of eating and drinking (VSED) has been used by, for example, those with neurological conditions. It has been viewed as a way to access assistance in dying when a condition is highly disabling but not rapidly fatal (8). This clause has some utility if the aim is to prevent those with eating disorders accessing assistance in dying. However, it does not provide full 'protection'. This is for two main reasons.

1. The use of the word 'voluntarily'. This term is fraught because of the highly complex debates that may occur around whether a person is engaging in eating disorder behaviours because of their own choice or irresistible compulsions caused by their mental disorder.

2. Eating disorders behaviour often involve more than just food. An important example are individuals with Type 1 diabetes and an eating disorder ('T1DE'). Sufferers may refuse to take their insulin for fear that it will make them put on fat. This leaves them at high risk of diabetic complications and early death. Similarly, people with all eating disorders may be reluctant to take even lifesaving medications that impact weight/contain sugar for any disorder e.g. steroids or potassium supplements.

Clause 2 (4)

For the avoidance of doubt, a person is not to be considered to be terminally ill only because they are a person with a disability or mental disorder (or both).

"Mental disorder" is not defined in the Bill as it stands. However, the Mental Health Act 1983 defines (in section 1(2)) a mental disorder as being "any disorder or disability of the mind,"[1] and we propose including this definition in clause 56 for clarity.

The mental disorder exception in clause 2(4) of the TIA Bill is strained because eating disorders are paradigmatic of disorders which are both profoundly physical *and* mental.

A psychological state may drive eating disorders but predisposing factors and the consequences are often physical. Of note, a person with anorexia may develop complications such as heart failure, renal failure and liver failure. These conditions, once they develop, could be understood as progressive physical illnesses which fall within the Bill's definition and yet they are the result of a mental disorder. Furthermore, this mental disorder may impact on the person's view of treatment of consequential physical health states or any other co-morbid condition. We expand on this last point below, but for present purposes the critical point is that there may come a time in relation to a person with anorexia when it cannot be said that they are 'only' a person with a mental disorder, such that the exception in clause 2(4) could not hold.

Mental capacity assessment in eating disorders

We address the issues around using the assessment of mental capacity as outlined in the Mental Capacity Act 2005 (MCA) in another briefing. In this document we discuss the particular problems around mental capacity assessment and eating disorders. During the passage of the Bill in the House of Commons, it became clear that there as an assumption on the part of some Parliamentarians that:

1. People with eating disorders have a mental disorder;
2. People with a mental disorder lack capacity to make decisions about ending their own life for purpose of the Bill;
3. Therefore the requirement for a capacity assessment is a safeguard against people with eating disorders accessing assistance in dying.

We suggest that it is important to make clear that this assumption relies upon a logical fallacy and an unsound evidential basis.

[1] Section 1 of the Mental Health Act 1983 will be amended in due course by the Mental Health Bill currently going through Parliament, but the definition of "mental disorder" will remain the same.

The logical fallacy is that having a mental disorder inevitably means that a person lacks capacity to make relevant decisions. As set out in the briefing on the MCA, it is only if a person has a mental disorder which causes them to be functionally unable to make a decision that they lack capacity.

The evidence is clear that that (1): capacity assessment in anorexia is complex and (2) international practice demonstrates that people with anorexia have been found to have capacity to end their lives within assisted dying frameworks.

Complexities of assessing mental capacity in those with eating disorders

It needs to be acknowledged that two decisions may be at play when considering assisted dying and eating disorders: the decision to request assistance in dying and the decision to refuse treatment in the form of nutrition and hydration (or other treatments impacting on body weight).

There are significant reasons to doubt a presumption of capacity for both these decisions including:

- Significant impact of starvation of the brain (9) – the brain alone requires around 500kcal per day to function;
- Literal reduction in brain size and reduction in brain cell connectivity;
- Cognitive issues: memory problems, cognitive rigidity (10), anxiety, depression, dominance of anorexic cognitions and identity, difficulty relating to others;
- Individuals with anorexia clearly describe experiences where they feel coerced by the 'anorexic voice' into valuing thinness above life itself.

However, people with anorexia are often judged to have the capacity to make relevant decisions, including around accepting nutrition and hydration. Some studies suggest that only one third have what is described as diminished mental capacity (11) (12). The reliability of capacity assessments in individuals with anorexia is low. The reasons for this include:

- Levels of lucidity are typically high;
- It can be difficult to disentangle the authentic self from the disorder;
- Decision making difficulties are specific to decisions around eating (11) (12);
- Capacity assessments can miss emotional difficulties such as underlying beliefs around being unworthy of help or powerful interpersonal dynamics complicating the assessment process.

A person with anorexia can lack capacity to make a decision about nutrition and hydration, but have capacity to make decisions about all other aspects of their life. It would therefore be possible for a person to lack capacity to make decisions about nutrition and hydration but to have capacity to decide to end their own life.

International practice around assisted death and eating disorders

A recent study reviewed all documented instances of assisted death for people with eating disorders. The authors searched academic literature and all publicly available government reports in jurisdictions where assisted dying is legal for people with psychiatric disorders plus the US. The authors found 60 relevant cases. In over 95% of these cases it was concluded that the individual's eating disorder was untreatable and all these individuals were assessed to have capacity to end their lives (13). This underscores that the current safeguards around the definition of terminality and capacity assessments

may not be sufficient to prevent those with eating disorders from accessing assistance in dying (as per the policy intention).

Conclusions

We have explained in our overarching briefing why we are not proposing amendments to address the scope of the Bill more generally. For similar reasons, we do not propose amendments to the Bill to address the matters set out above, because we do not consider that it is possible to do so without significantly changing the policy of the Bill.

In considering the policy of the Bill in relation to eating disorders, we also stress that Parliamentarians will need to consider the potential knock-on consequences of the management and treatment of eating disorders more generally through the 'messaging' of the Bill around the approach to such disorders.

Further information

For more detail about any of the matters set out above, please contact lucy.a.stephenson@kcl.ac.uk.

More information about CLADD can be found here.

Alex Ruck Keene maintains a resources page on the TIA Bill here.

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