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Anorexia Nervosa and the Terminally Ill Adults (End of Life Bill)

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Executive Summary

This memo considers how the *Terminally Ill Adults (End of Life) Bill* may apply to individuals with anorexia nervosa (hereafter anorexia) if enacted in its current form. Although anorexia is classified as a mental disorder, questions remain about whether physical deterioration associated with the illness could be interpreted as meeting the Bill's criteria for terminal illness, particularly in cases where treatment is refused.

A recent study found that individuals with anorexia have died by assisted death in three U.S. states that limit eligibility to terminal illness[1]. These cases drew on the emerging and contested idea of "terminal anorexia," which has been proposed in academic literature but is not recognised as a formal diagnosis. The concern is that similar reasoning could be applied under this Bill, even if that is not Parliament's intention. This memo aims to:

1. Outline flashpoints and key questions relevant to anorexia in the current draft of the Bill
2. Examine proposed amendments that may help to mitigate risks to those with eating disorders
3. Provide relevant clinical information about anorexia to inform these considerations

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1. Could the Bill Be Interpreted to Include Anorexia?

Anorexia is a mental disorder that can lead to severe physical deterioration and is known as the most lethal psychiatric disorder[2]. Suicide is the second leading cause of death in anorexia; individuals with anorexia are up to eighteen times more likely to die by suicide than their age-matched peers[3].

Clause 2 of the Bill states that assisted dying would be lawful for people who are terminally ill. It defines terminal illness as:

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

Below we outline how this 'common sense' definition of terminally ill could be interpreted in a way that may contravene the intent of the law, based on evidence from jurisdictions where assisted dying is legal.

The emergence of the concept of 'terminal anorexia'

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[1] Roff, C., & Cook-Cottone, C. (2024). Assisted death in eating disorders: a systematic review of cases and clinical rationales. Frontiers in Psychiatry, 15.

[2] Treasure J, Duarte TA, Schmidt U. Eating disorders. Lancet. 2020;395(10227):899-911.

[3] Smith AR, Zuromski KL, Dodd DR. Eating disorders and suicidality: what we know, what we don't know, and suggestions for future research. Curr Opin Psychol. 2018 Aug;22:63-67.

The term ‘terminal anorexia’ is a new and contested concept, and there is not currently professional consensus on its validity or application within the eating disorder field.

It was introduced in a case series published in the *Journal of Eating Disorders*[4], which described the deaths of three individuals with anorexia. The authors proposed criteria for a new diagnostic subcategory, “terminal anorexia,” and argued that this subgroup *“should be afforded access to medical aid in dying in locations where such assistance has been legalized — just like other patients with terminal conditions”*[2]. They suggested that formal recognition of this category would facilitate access to assisted death, as well as *“palliative care, hospice care, and emotional and practical resources for loved ones”*[2].

Two of the deceased women described in the study were deemed eligible for, and died by, assisted death in California and Colorado — jurisdictions where it is legally restricted to terminal illness. The question of whether ‘terminal anorexia’ met the legal criteria for assisted death in these states has not been tested in the courts. In both states, the law grants immunity from civil, criminal, and professional liability to those who act in “good faith” under the Act. As a result, there are limited mechanisms to independently scrutinise or legally challenge these cases, even if eligibility appears to fall outside the scope of the law.

This paper generated considerable controversy, and the lead author on the paper has publicly apologised for any harm it may have caused. However, the original article remains publicly accessible in an open access journal. As of this writing, it has been accessed over 97,000 times and featured in 49 major news outlets. In the public domain, it has been presented as a controversial new diagnostic category, rather than a theoretical proposal without broad professional consensus. In light of this controversy, the question before Members of Parliament is whether the bill could be similarly interpreted to include “terminal anorexia” within its scope.

Can a Six-Month Prognosis Be Determined in Anorexia Nervosa?

Under the Bill, a person may be considered terminally ill if their death is reasonably expected within six months. While prognostic estimates in medicine are often made under conditions of uncertainty, this is significantly amplified in the context of eating disorders, where illness trajectories are variable and shaped by complex psychological, social, and biological factors[5]. While elevated risk of mortality is well established, individual outcomes are difficult to predict with precision[6]. Research suggests recovery remains possible, even after 20+ years of illness[7]. However, even experienced clinicians struggle to accurately and reliably predict who will recover, who may die, or within what timeframe.

Of those diagnosed with Anorexia, 50-80% make a full or partial recovery[8], although this process may take around 10 years[1]. There is evidence that a good prognosis is more likely for those whose eating disorder is promptly recognised and treated (i.e. within the first 3 years) and nutritional restoration achieved[9]. Within the eating disorder professional community, treatment for these first presentations is relatively uncontroversial and watchful waiting is avoided.

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4 Gaudiani JL, Bogetz A, Yager J. Terminal anorexia nervosa: three cases and proposed clinical characteristics. Journal of Eating Disorders. 2022;10(1):23.

5 Frostad S, Rozakou-Soumalia N, Dârvariu Ş, Foruzesh B, Azkia H, Larsen MP, Rowshandel E, Sjögren JM. BMI at Discharge from Treatment Predicts Relapse in Anorexia Nervosa: A Systematic Scoping Review. J Pers Med. 2022 May 20;12(5):836.

6 Miskovic-Wheatley, J., Bryant, E., Ong, S.H. et al. Eating disorder outcomes: findings from a rapid review of over a decade of research. J Eat Disord 11, 85 (2023).

7 Eddy KT, Tabri N, Thomas JJ, Murray HB, Keshaviah A, Hastings E, et al. Recovery from anorexia nervosa and bulimia nervosa at 22-year follow-up. The Journal of clinical psychiatry. 2017;78(2):17085.

8 Fichter MM, Quadflieg N, Crosby RD, Koch S. Long-term outcome of anorexia nervosa: Results from a large clinical longitudinal study. Int J Eat Disord. 2017 Sep;50(9):1018-1030.

9 Mills R, Hyam L, Schmidt U. Early intervention for eating disorders. Curr Opin Psychiatry. 2024;37(6):397-403.

For the approximately 20% of those who develop a longstanding eating disorder[10], there is far less consensus on the approach to take towards treatment[11]. Clinicians may weigh up the relative benefits of forced treatment to help the person eat and regain weight, versus those aimed at harm reduction and quality of life[12]. In these cases, establishing prognosis is particularly challenging. There is limited evidence to determine if further treatment is futile, and outcomes depend on whether the individual receives and is able to engage with treatment. Prognosis may also be influenced by the doctor's attitudes, the individual's characteristics, and the doctor-patient relationship[13].

Does the Bill Exclude Anorexia Because it is a Mental Disorder?

Anorexia is classified as a mental disorder and is largely treated within mental health services in the UK. In Clause 2(3), the Bill states:

> *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).*

It may therefore be presumed that individuals with anorexia would not be eligible to access assisted dying. However, this assumption may be inaccurate, for the following reasons:

- Anorexia is a mental disorder with severe physical consequences, which requires medical as well as psychiatric treatment. It therefore puts strain on the conceptual divide between physical and mental disorder — as do other conditions, like dementia and delirium.
- A person with anorexia may also have a terminal illness unrelated to their eating disorder.
- Anorexia can affect how someone manages another health condition, making a condition that would otherwise be manageable with treatment life-threatening.
- A person who requests assistance to end life may present primarily with a physical condition (e.g., liver failure), which is in fact a sequelae of underlying anorexia.
- Most significantly, the Bill states that individuals with mental disorders may still be considered terminally ill if they meet the definition in Clause 2(1).

This final reason refers to the following text, which was added to Clause 2(3) by an amendment 181 in Committee Stage:

> *Nothing in this subsection results in a person not being regarded as terminally ill for the purposes of this Act if (disregarding this subsection) the person meets the conditions in paragraphs (a) and (b) of subsection (1).*

As written, Clause 2(3) appears to clarify that a mental disorder *on its own* is not sufficient to meet the definition of terminal illness. However, it also states that having a mental disorder does not *prevent* someone from being considered terminally ill if they otherwise meet the criteria in Clause 2(1). This wording suggests that a person with anorexia may be considered terminally ill under the provisions of the bill if they otherwise meet the criteria in Clause 2(1), but that mental illness by itself cannot be the basis for eligibility. The Impact Assessment affirms this: "having a disability or mental disorder does not prevent a person from being regarded as terminally ill if they meet the definition of terminally ill in Clause 2."

If Parliament intends that anorexia and its physical sequelae should not be grounds for accessing assisted dying, further clarification in the Bill may be needed.

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[10] Steinhausen H-C. The Outcome of Anorexia Nervosa in the 20th Century. American Journal of Psychiatry. 2002;159(8):1284-93.

[11] Wildes JE, Forbush KT, Hagan KE, Marcus MD, Attia E, Gianini LM, Wu W. Characterizing severe and enduring anorexia nervosa: An empirical approach. Int J Eat Disord. 2017 Apr;50(4):389-397.

[12] Dobrescu SR, Dinkler L, Gillberg C, Råstam M, Gillberg C, Wentz E. Anorexia nervosa: 30-year outcome. Br J Psychiatry. 2020 Feb;216(2):97-104.

[13] Ferrand A, Poleksic J, Racine E. Factors Influencing Physician Prognosis: A Scoping Review. MDM Policy & Practice. 2022;7(2).

Could the physical consequences of an eating disorder be considered terminal?

The physical consequences of anorexia can be life-threatening[12]. One potential scenario is that a person might request assisted dying and present primarily with of a condition that appears to meet common sense definitions of terminal illness (e.g. kidney or liver failure). However, the reality might be that this condition is a consequence of anorexia driven by malnutrition, dehydration, and electrolyte imbalance, rather than a progressive and untreatable disease process. Anorexia can be an illness where people find it challenging to disclose and be open about the true extent their behaviours, further complicating the clinical picture.

Many complications from anorexia — including kidney, heart, or liver dysfunction — can be reversible with nutritional rehabilitation and sustained care[14]. In clinical practice the straight forwardness of providing this care may depend on whether the person is willing to receive it. Individuals with anorexia may refuse life-saving interventions, such as nasogastric feeding, as they may prioritise maintaining a very low body weight above all else.

In these scenarios there may be hard decisions to be made about the use of compulsory treatment, particularly if it is thought that medical treatment/nutritional restoration could be lifesaving (and determining this might be very difficult). In England and Wales this would involve considering treatment under the Mental Capacity Act 2005 and/or the Mental Health Act 1983. If it is determined that compulsory treatment is not appropriate under these frameworks (as has occurred in some Court of Protection cases) the physical consequences of anorexia may predictably lead to death.

Can a person become terminally ill by voluntarily stopping eating and drinking?

In some U.S. states, voluntarily stopping eating and drinking — known as VSED — has been discussed as a means of becoming eligible for assisted death in cases where individuals would not otherwise meet the criteria.[15]. Some authors have argued that by refusing food and fluids, a person with an otherwise non-terminal illness can accelerate their physical decline to meet the legal requirement of a six-month prognosis. The rationale is that malnutrition and, more immediately, dehydration will naturally result in death within 8 to 14 days[15]. In these jurisdictions if an individual has capacity (according to their legal frameworks) to refuse nutrition and hydration, it cannot be lawfully imposed. Thus, some scholars argue a doctor can reasonably conclude their death is probable within six months[15].

In an article in the *Journal of the American Geriatrics Society,* legal scholars described VSED as 'a bridge to Medical Assistance in Dying'[16]. They reported the case of a 45-year-old woman in Oregon with early-stage dementia who did not initially qualify for assisted death[16]. After five days of VSED, her doctors assessed her life expectancy to be less than six months, and deemed her eligible for assisted death under Oregon's Death with Dignity Act.

An ethics consultation published by the Academy of Aid-in-Dying Medicine similarly stated that "*there is nothing in the letter of the law of any of the U.S. states' aid in dying bills that explicitly prohibits accepting VSED as a terminal diagnosis to qualify for aid in dying"*[17]. This interpretation has, in practice, enabled individuals with chronic but non-terminal conditions to become eligible for assisted death in some U.S. states by accelerating their physical decline through VSED. The most commonly cited example is dementia — but the same reasoning could be applied under the Bill currently before Parliament to anorexia, a condition in which refusal of food is itself a symptom of the illness.

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[14] Westmoreland P, Krantz MJ, Mehler PS. Medical Complications of Anorexia Nervosa and Bulimia. Am J Med. 2016 Jan;129(1):30-7.

[15] Pope, T. M., & Brodoff, L. (2024). Voluntary stopping eating and drinking as a bridge to medical aid in dying. Journal of Medical Aid in Dying Medicine, 1(2), 76-86.

[16] Pope, T. M., & Brodoff, L. (2025). VSED bridge to MAID: Spotlighting better end-of-life options. Journal of the American Geriatrics Society, 73(1), 314–315.

[17] Cederquist, L., et al. (2023). Voluntary stopping of eating and drinking and medical aid in dying (Ethics Consultation Case No. 5). American Clinicians Academy on Medical Aid in Dying.

Can a person become terminally ill by refusing medical treatment?

This raises a broader question: can a person be considered terminally ill if they decline medical treatment that could — if not reverse — significantly alleviate or help manage their condition? This question has implications across a range of eating disorders, not just anorexia.

One example is 'T1DE' (Type 1 Diabetes and Disordered Eating), a lesser-known but serious illness involving both physical and psychological components. Like anorexia, it challenges the conventional distinction between physical and mental illness. Individuals with T1DE have insulin-dependent diabetes and may engage in disordered eating behaviours — such as bingeing on high-sugar foods — followed by deliberately restricting insulin to avoid weight gain. While type 1 diabetes is irreversible it is manageable with insulin therapy. If insulin is withheld, however, lethal complications may rapidly result. This raises an important question for Parliament: could a person with T1DE who refuses insulin be considered terminally ill under this Bill, despite having a condition that is otherwise manageable with standard treatment?

Similar concerns arise in the context of binge/purge subtype anorexia. For example, individuals who frequently induce vomiting — common in both anorexia and bulimia — are at risk of dangerously low potassium levels, which can trigger fatal heart arrhythmias. This is medically manageable with potassium supplementation, but fear of calories or weigh gain may lead individuals to refuse these interventions.

These examples illustrate the questions that arise when applying the definition of terminal illness currently in the bill to disorders where physical deterioration is a result of a treatable mental disorder, and where refusal of treatment may be driven by the illness. Without clearer provisions, there is a risk that these individuals could fall within the scope of eligibility for assisted dying.

Can individuals with anorexia be judged to have capacity to end their life?

Mental capacity assessment is a proposed safeguard in the current Bill. It is important to note under the Mental Capacity Act 2005 a person can have the capacity to make one decision but not another, and their capacity can change over time. In the case of Anorexia, mental capacity assessment may be particularly complicated. We have discussed two decisions that might need to be considered: (1) does the person have mental capacity to refuse treatment (i.e. nutrition)? and (2) does the person have capacity to decide to end one's own life?

A recent review of 60 individuals with eating disorders who died by assisted death abroad found that all were assessed to have capacity to decide to end their lives[1]. Although these assessments occurred outside the Mental Capacity Act framework used in England and Wales, they raise important questions about how capacity to end one's life is assessed in practice. It remains unclear whether a person judged to not have capacity to make decisions about treatment for anorexia — and for whom compulsory treatment is deemed not in their best interests — could nonetheless be considered to have capacity to request assisted death.

There are significant reasons to doubt presumptions of capacity to refuse treatment or end one's life in a person diagnosed with anorexia including:

- Significant impact of starvation of the brain[18]
- Brain alone requires 500kcal per day to function
- Literal reduction in brain size, reduction in brain cell connectivity

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[18] Keeler JL, Patsalos O, Chung R, Schmidt U, Breen G, Treasure J, Hubertus H, Dalton B. Short communication: Serum levels of brain-derived neurotrophic factor and association with pro-inflammatory cytokines in acute and recovered anorexia nervosa. J Psychiatr Res. 2022

- Cognitive issues: memory problems, cognitive rigidity[19], anxiety, depression, dominance of anorexic cognitions and identity, difficulty relating to others[20]
- 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 decisions about their treatment and care, including treatment refusal:

- Some studies suggest that only one third have diminished mental capacity[21]
- General cognition and function often well preserved
- Difficulties commonly highly decision specific to decisions around weight[2]
- Challenging to disentangle the authentic self from the disorder
- Underlying beliefs around being unworthy of help
- Capacity assessments focus on cognitive rather than emotional difficulties
- Reliability of capacity assessments in individuals with anorexia is low
- Powerful interpersonal dynamics may complicate the assessment process.

2. Proposed amendments to address risks to those with eating disorders

The following three amendments, which have been tabled for Report Stage, may help to mitigate (although not eliminate) risks to individuals with eating disorders:

Amendment 14

> ***Clause 2, page 2, line 6, at end insert—***
> *"(1A) 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 amendment may help mitigate the risk that a person with anorexia could be deemed eligible for assisted death on the basis of severe malnutrition resulting from food refusal. It may also play an important role in anticipating and preventing the use of VSED as a pathway to eligibility for assisted death in other cases where the individual would not otherwise meet the criteria.

However, this amendment may not go far enough to mitigate the risks to individuals with other types of eating disorders (e.g., T1DE, Bulimia Nervosa). As discussed above, there are scenarios in which a person with an eating disorder may refuse potentially life saving treatment beyond nutrition, and make a request for assistance in dying. Related to eating disorders this might include:

- A person with T1DE who refuses insulin due to fear of weight gain, resulting in elevated blood glucose levels which can be life-threatening if not treated.
- A person with an eating disorder alongside a treatable/manageable co-morbid physical health condition, who refuses treatment due to illness-related beliefs
- Situations where the physical sequelae of eating disorders which do not primarily involve food refusal are nonetheless are life-threatening if treatment is not provided.(e.g. if there are purging behaviours which cause low blood potassium levels)

Amendment 38, when read alongside Amendment 14, may help to address the risks outlined above:

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[19] Tchanturia K, Davies H, Roberts M, Harrison A, Nakazato M, Schmidt U, et al. Poor cognitive flexibility in eating disorders: examining the evidence using the Wisconsin Card Sorting Task. PloS one. 2012;7(1):e28331.

[20] Stedal K, Scherer R, Touyz S, Hay P, Broomfield C. Research review: Neuropsychological functioning in young anorexia nervosa: A meta-analysis. Journal of Child Psychology and Psychiatry. 2022;63(6):616-25.

[21] Elzakkers IF, Danner UN, Hoek HW, Van Elburg AA. Mental capacity to consent to treatment in anorexia nervosa: explorative study. BJPsych open. 2016;2(2):147-53.

Amendment 38:

> *Clause 2, page 2, line 6, at end insert—*
> *"(1A) 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 refusing standard medical treatment or taking any action intended to bring about a state of terminal illness."*

Another strategy could be to amend the bill to further clarify the definition 'inevitably progressive' in order to restrict the definition of 'terminal' within the Bill to exclude these kinds of scenarios. This potential clarification is outlined below:

> *Clause 2, page 2, line 6, at end insert—*
>
> *'for the avoidance of doubt, an illness shall be considered to be inevitably progressive solely where any treatment that is available cannot reverse the condition, but can only alleviate the symptoms of that illness.*

This would clarify that an illness should only be considered "inevitably progressive" where no treatment is available to reverse it. It may help to ensure individuals with eating disorders or other conditions, such as diabetes, cannot be deemed terminally ill by refusing treatment for a condition that would otherwise be manageable or reversible.

Finally, Amendment 32 highlights the importance of psychiatric expertise in assessing requests for assisted dying. This could help reduce the risk that a co-occurring or underlying eating disorder is overlooked — particularly given that individuals with eating disorders may not disclose relevant behaviours.

Amendment 32

> *Clause 10, page 8, line 6, at end insert—*
> *"(aa) is a practitioner approved as having special experience in the diagnosis or treatment of mental disorder for the purposes of subsection (2) of Section 12 (General provisions as to medical recommendations) of the Mental Health Act 1983,"*

This amendment may also ensure that the complexities of capacity assessment in the context of eating disorders are better understood by the independent doctor. A future code of practice could clarify that, where an eating disorder is present, input from a psychiatrist with relevant expertise should be sought.

Conclusion

Eating disorders — anorexia in particular — expose a difficult and unresolved problem in the *Terminally Ill Adults (End of Life) Bill*. Although anorexia is a treatable mental disorder, physical deterioration caused by the illness, combined with treatment refusal, may result in cases that appear to meet the legal definition of terminal illness. Several amendments have been proposed to address this concern, but no single amendment fully resolves it. Anorexia raises deeper questions about how the Bill defines terminal illness and situations in which a person's request for death may result from the interplay between physical decline and mental health symptoms. If Parliament does not intend for these cases to fall within the scope of the Bill, clearer provisions may be required.

APPENDIX: CLINICAL BACKGROUND

What is Anorexia Nervosa?

Anorexia Nervosa is one type of eating disorder. Key diagnostic criteria (from International Classification of Disease 11) include :

- Significantly low body weight (Body Mass Index (BMI) below 18.5 in adults)
- Persistent pattern of restrictive eating or behaviours aimed at establishing or maintaining a low body weight (e.g. restrictive eating, self-induced vomiting, over activity, medication misuse)
- Excessive preoccupation with body weight or shape

How Prevalent is Anorexia Nervosa?

- During their lifetime up to 4% of females and 0.3% of males suffer from Anorexia Nervosa[22]
- People diagnosed with Anorexia who require outpatient care have a Standardised Mortality Ratio of 5.9 ie they are 5.9 times more likely to die when compared to other members of the same population who do not have a diagnosis of Anorexia Nervosa[23].

What are the Causes and Maintaining Factors of Anorexia Nervosa[1]?

Biological	Psychological	Social	Behavioural
Genetics	Personality traits (e.g. attention to detail, perfectionism)	Parental eating problems	Over control of weight and eating
Gender (higher incidence in females)	Cognitive rigidity	Bullying	Attempting to cope by avoidance or perfectionism
Neurodiversity e.g. Obsessive compulsive or autistic spectrum traits	High ability to delay rewards	Trauma	Social isolation
Behavioural susceptibility to appetite repression	Difficulty in social interactions	Cultural idealisation of thinness	Impaired physical, mental and social quality of life
Metabolic tendency towards lower fat stores	Body image disturbance		
Environmental influences during pregnancy and early infancy	Difficulties feeling and recognising emotions		

[22] Keski-Rahkonen A, Mustelin L. Epidemiology of eating disorders in Europe: prevalence, incidence, comorbidity, course, consequences, and risk factors. Current opinion in psychiatry. 2016;29(6):340-5.

[23] Keshaviah A, Edkins K, Hastings ER, Krishna M, Franko DL, Herzog DB, et al. Re-examining premature mortality in anorexia nervosa: a meta-analysis redux. Comprehensive psychiatry. 2014;55(8):1773-84.

What are the Consequences of Anorexia Nervosa?

Biological	Psychological	Social
Brain: Reduction in brain tissue	Memory problems	Social isolation
Heart: low blood pressure, low heart rate, abnormal heart rhythms, heart failure	Cognitive rigidity	Interrupted life course (e.g. interruptions in opportunities in education, work progression, family life and social life)
Metabolic: Low blood sugar, low blood potassium and sodium levels (this can cause sudden death due to abnormal heart rhythms)	Depression	
Digestion: Oesophageal tears (if vomiting behaviour)		
Blood: bone marrow suppression, anaemia		
Kidney: Acute kidney injury, kidney failure, kidney stones		
Liver: Liver failure (because the liver auto digests itself if there is no external nutritional intake)		