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1. Main cause of suffering: ASD/ID only

2013-21 Male, 60s, ASD

The patient was an utterly lonely man who had lived a failed life. He reacted to everything with great panic, even to the simplest situations. The panic was then very visible. He argued with everyone who was not a social worker (or "care professional"). The patient had become completely stuck in an isolation that he found more and more painful. He was tired and he couldn't find rest anywhere. Also, he could not adapt to new situations. His health deteriorated and he had to move to an assisted living facility. This thought was an abomination to him. It was also very difficult for the patient to oversee how to organise his daily life. The patient had experienced his suffering as unbearable for years.

2014-77 Male, 30s, ASD

The patient's suffering consisted of being constantly preoccupied with thoughts on many and different levels in his head and not being able to close off stimuli or lines of thought. He found that exhausting. He wanted to clear his mind and have peace. The patient suffered from the great need for closeness to others, while he was unable to maintain long-term social contacts. This was because he misjudged interactions and had a tendency to behaviour that crossed boundaries. He could react to things spontaneously and violently, sometimes extremely so. This often led to problems. However, the patient could not learn from these experiences. He was frustrated by his "forbidden" feelings, such as desire for sexual intimacy. He suffered from his incessant craving for meaningful relationships and his recurring frustration in this area due to his inability to adequately deal with closeness and social contacts. His damaged development and resulting low frustration tolerance and lack of basal sense of security contributed to his diminished ability to learn to cope with the limitations of his illness.

2018-12 Female, 80s, ID

ID = major contributing factor

An increasing tardive tic disorder for more than seven years before death. There was talk of producing continuity involuntary vocal sounds. Initially it was about beeping and sighing, but eventually the image developed into frequent, screaming loudly and uncontrollably. The patient had a learning disability and had been known to have recurrent depression for much longer (…) The patient's suffering consisted of the almost constant, irrepressible urge to make noise. She frequently emitted high, short screams. As a result, she often had a hoarse voice and pain in throat and head. She got very tired from screaming. The patient slept badly at night as well. She suffered from the social isolation that she had ended up in as a result of her behaviour. She disturbed meetings with he screams. People found her repulsive and no one wanted to be near her. She was unable to give meaning to her existence in any other way. She no longer experienced any quality of life.

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2018-24 Male, 18-30, ASD

The patient's suffering consisted of the realization that, despite his above-average intelligence - which also sharpened that realization – he could not lead a 'normal' life. He quickly became overstimulated and could hardly maintain himself. In particular, he could not, or only with great difficulty, perform daily activities that required contact with third parties, and these then exhaust him completely. Making choices or carrying out simple instructions was extremely difficult, if not impossible, because of his rigid way of thinking and resulting enormous need for clarity, certainty and structure; this paralyzed him in his functioning. Because of his inability to put himself in other people's shoes and understand them, it was also impossible to form intimate relationships, although the patient wanted to. He suffered from the hopelessness of his situation and the lack of any future perspective.

2019-99 Female, 30s, ASD

Diagnosed with a severe form of Autism Spectrum Disorder (ASD) several years before death, with rigid and compulsive thinking patterns, automulation and chronic suicidality.(…) The patient's suffering consisted of extreme hypersensitivity to stimuli, constant worrying and compulsive fears. This made it very difficult to cope socially and had severely limited tension-regulating skills. She couldn't bear anything unexpectedly. Unclarity, uncertainty and the slightest disturbance constantly unbalanced her. The patient's world was limited by this, which prevented her from developing. The patient, who was an intelligent woman, fought a hard, futile struggle every day to keep her balance, with all the help she was offered. She suffered from the hopelessness of her situation, the forced passivity and the constant feeling of having to to survive. The patient experienced no control over her life, a lack of quality of life and suffered from the despair that life brought with it.

2020-27 Male, 70s, ASD + ID

A mild intellectual disability with an IQ of 70 with additional ASD features. Because he could never keep up with society, he had become insecure and had recurrent depressions with anxiety, which made him withdraw more and more. Due to his intellectual disability he experienced a great pressure of the world on him which he could not handle. Due to his autistic features he found it increasingly difficult to cope with changes around him. With age, his coping capacity ("draagkracht") decreased and the fear increased, so that eventually unbearable suffering ensued.(…) The anxiety and mood problems also seemed to be secondary to the lifelong developmental problems with his intellectual disabilities (…) Because of his mild intellectual disability, life gave him too much tensions due to insecurity. The medication he was given made him feel empty; he experienced that life contained less and less. The patient was so insecure and anxious that he could not lead a normal life in the residential care center. Because of this, he became increasingly gloomy. With age, his coping capacity ("draagkracht") decreased and the fear increased, which ultimately led to unbearable suffering.

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2020-44 Male, 40s, ASD

In his adolescence he went through a psychosis, possibly induced by substance abuse (…) About twenty years before death, the diagnosis of ADHD was established and two years later an autism spectrum disorder (ASD).(…) The patient suffered from the fact that he constantly felt tense, restless, lifeless and aimless. He achieved little. Before going outside, for example to do some shopping, he first had to gather courage. His attempts to participate in society were all disappointing. The patient felt unhappy and felt as if he had been covered by 'a slimy layer of misery'. He suffered from the deterioration of his functioning, the feeling of not belonging anywhere and loss of quality of life. He lived only for his cat and could no longer cope with his life with all its limitations.

2021-26 Male, 20s, ASD

At its core, his suffering amounted to the patient not being able to love himself. There was a deeply rooted selfishness, where he felt himself to be 'a defective product'. The patient was unable to get along with himself or others, which made him live a very socially isolated life. He quickly became overstimulated and then became severely tense or frustrated and then proceeded to self-harm. The patient was not able to accept to his limitations, which frustrated and depressed him immensely (…) The doctor concluded that there were no more realistic treatment options for the patient. Despite the treatments, the patient's burden of suffering was not reduced. He couldn't accept his autism and he continued to feel uncontrollably worthless and damaged. The doctor felt supported in this regard by the practitioners of the patient's Autism Team.(…) At the same time, the patient longed for social contacts, but was unable to connect with others. This reinforced his sense of loneliness. The consequences of his autism were unbearable for him. Over the years, the patient was proved to be unable to accept his limitations, which frustrated and depressed him immensely. The prospect of having to live on in this way for years was an abomination to him and he could not bear it.

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2. Main cause of suffering: ASD/ID + Somatic

- ASD/ID as one of the main causes of suffering in itself, along with somatic problems
- ASD/ID as main factor why patient was not coping with somatic problems
- NOTE: these could be categorised as ASD/ID only. These somatic problems would have been part of possible life for most of the population

2015-83 Female, 60s, ID

ID = major contributing factor

The patient had suffered from tinnitus for 10 years. (…) The patient suffered from hyperacusis and developed psychological complaints, such as fear of sound. (…) The patient's suffering consisted of the feeling of being constantly bombarded by all kinds of different and terrible sounds. (…) However, the patient's personality traits and her intellectual disabilities resulted in an inability to benefit from psychological or psychiatric help. (…) With her primitive mind, the patient was only focused on the complete removal of the tinnitus. The moment until her realized "I will never get rid of it", her suffering had become hopeless and unbearable for her and she was only focused on euthanasia.

2016-48 Female, 90s, ASD + ID

ASD = major contributing factor (reason for not coping with deteriorating health)

A combination of age-related disorders. There was deafness, visual impairment, osteoarthritis and osteoporosis. (…) The patient's suffering consisted of debilitation, general impairment, physical impairment resulting in loss of mobility and cognitive decline resulting in an increase of the pre-existing communicative impairments that resulted from the autistic disorder. The patient was no longer interested in the world around her and was no longer able to enter into social contacts. She was care and contact averse. The patient spent her days in isolation in her room and in fact was only really just occupied with her activities of daily living (ADL). She refused help from others because she wanted to continue doing everything herself - according to fixed rituals - even when that was almost impossible. She suffered from the increasing loss of control over her life. (…) The patient's coping capacity had diminished due to her psychiatric condition, so that she experienced the general deterioration due to degeneration as unbearable.

2018-14 Female, 80s, ASD

The routine that she had introduced into her life also gave the patient something to hold on to when dealing with a world that was complex for her. Because of her physical limitations it had become increasingly difficult for the patient to give meaning to her existence. After a fall approximately one year before death, the patient was wheelchair-bound and admitted to a nursing home. As a result, she had to give up a beloved pet and precious possessions related to her hobbies. Moreover, the physical deterioration made it impossible for the patient to give meaning to her life in another way. Ultimately, the patient was largely immobilized. She spent large parts of the day lying in bed and was ADL dependent. The patient was unable to cope with the loss of her fixed patterns and with her

dependence on care. She was frustrated, desperate and sad because of this. She felt that everything had been taken away from her and had fallen into social isolation.
The progressive physical deterioration and the lifelong inability to deal with her environment other than in fixed patterns, caused unbearable suffering for the second consultant.

2018-26 Male, 90s, ASD

ASD = major contributing factor (reason for increasing loneliness and not coping with deteriorating health)

The patient had always lived as a loner, but with aging he seemed to get stuck. The patient was an erudite man who had his own rigid vision of the world. He also liked to propagate this vision to his fellow human beings. They had little interest in them and as a result the patient felt misunderstood, excluded, desperate and lonely. (…) The patient's suffering consisted of a combination of severe sensory impairment, general physical deterioration, debilitation, being confined to bed and the consequences of his ASD. He no longer experienced any quality of life. (…) The consultant noted that the patient was suffering unbearably at that time due to the loneliness and severe sensory impairments.

2019-22 Male, 70s, ASD

ASD = main cause alongside mental health and somatic causes, and also contributes to inability to cope with those

Suffered unbearably from a combination of psychological and somatic disorders for which all treatments were exhausted, including an Autism Spectrum Disorder (Asperger's), an obsessive-compulsive disorder, COPD, diabetes mellitus, and vascular disease.(…) The patient suffered from his inability to participate in society due to his limitations. He had always felt out of place in the world and had a euthanasia wish for years. The patient had constant obsessive thoughts, which did have a function for his autism; they gave a kind of relaxation from the stress he was constantly experiencing. The patient was unable to live among people because he quickly became overstimulated. As a result, he lived isolated within the clinic and did not participate in group activities. He could no longer fulfil household chores within the clinic, due to exhaustion. The patient found the world too complex for him. In addition, as the years progressed, the patient had also developed many physical discomforts. He had pain in his legs and was short of breath very quickly. Due to these physical complaints, the patient was barely able to function. He could only take shuffling steps. The physical complaints increased in severity over time and his coping capacity decreased as a result.

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2020-114 Female, 70s, ASD + ID

A gastric carcinoma was diagnosed more than a year and a half before death. She was treated for this by means of a partial gastric resection. Gallstones were diagnosed nearly three months before death. The patient emphatically refrained from treatment of this. Several weeks before death, the patient was diagnosed with a severe autism spectrum disorder (ASD). The patient's suffering consisted in not being able to cope with the adjustments in her routines that the new limitations brought with them. Due to the partial gastric resection, the patient should actually eat small amounts several times a day, but she was unable to do this because of her rigid belief that she should eat three times a day on a regular basis. Patient lost more and more weight, became more and more limited in her functioning and became increasingly dependent on the help of others. There was increasing loss of strength and stamina, intense fatigue, abdominal and back pain, nausea, vomiting and cachexia. The fact that the cancer had been cured made little difference to the patient, the consequences of the surgery and the profound changes in her life she experienced as impossible and unbearable.

2020-33 Male, 50s, ASD

Often gloomy, found it difficult to enjoy, could not tolerate stimuli, had a lot of trouble with social contacts and experienced the world as one complex condition that he poorly understood and had little control over. Eight years before the death, the patient was diagnosed with an Autism Spectrum Disorder (ASD), type Asperger.(…) Three years before the death, after attending a concert, the patient developed an annoying beep in both ears and a hypersensitivity to sound. The diagnoses of tinnitus and hyperacusis were made.(…) He had less and less energy for activities and social contacts. Yet he couldn't be alone very well either, because then there was nothing to distract him from the beep sound. The only thing that brought relief was cycling, then the beeping sound was less. The beep had taken over the patient's life and overpowered everything. Partly due to his ASD, despite all therapies he'd been following, the patient was unable to withdraw from the beep or ignore it. He felt desperate, longed to be relieved of his suffering and wanted to die by euthanasia.

2020-46 Female, 80s, ASD

the loss of her independence after the hip fracture. After refusing an operation, she became completely dependent on care. She started with the physiotherapy offered to her, but unfortunately that did not bring any improvement. Her immobility, her severe hardness of hearing and her personality with ASD characteristics / social incapacity also made her end up in social isolation. The patient also had a lot of pain that was difficult to control.(…) The unbearable suffering was palpable to the doctor because the patient had been suffering existentially for many years as a result of her emotional limitations (ASD characteristics) and having to live with a great emotional burden. Her coping had always consisted of emotionally flat behaviour and chronic self-absorption. Now there were loss of independence, pain, progressive cognitive decline and severe hearing loss, which left the patient completely socially deprived.

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3. Main cause of suffering: ASD/ID + Mental Health

- ASD/ID as one of the main causes of suffering in itself, along with mental health problems
- ASD/ID as major contributing factor why patient was not coping with mental health problems

2017-24 Male, 40s, ASD

The patient's suffering consisted of social phobias, paranoid delusions, relationship ideas, hallucinations, dissociative phenomena and depression. The patient did not feel comfortable in company and had deep-seated feelings of displacement, loneliness, fear and alienation. He always experienced a war in his head, although others could not always notice what was going on in his head and how anxious he was feeling. He had obsessive thoughts that he couldn't control. When the patient was overstimulated, intense fears arose that were accompanied by agitation and physical symptoms such as palpitations. Patient could become very suspicious with delusions that he was being watched. When he heard a car honk on a street, it was a warning intended for him, or when he heard people talking in the street, it was about him, et cetera. His daily life consisted of avoiding stimuli; patient hardly went outside, lay in bed almost all day and felt worthless. He did not always recognize family or he thought that they also wanted to do something to him. The patient also did not feel safe in his own bedroom. He suffered from the hopelessness of his situation. The patient experienced his suffering as unbearable.

2017-80 Female, 18-30, ASD

ASD = main cause of suffering in itself, along with mental health issues

Suffers from anxiety, compulsion, mood and emotion regulation problems for about one year. Four years before her death, she was found to have additional personality problems with borderline, dependent and avoidant traits. Three years before death, patient was diagnosed with PDD-NOS (pervasive developmental disorder - not otherwise specified) of the type McDD (multiplex complex developmental disorder).(…) The patient's suffering consisted of continuous feelings of fear, misery and suicidal thoughts. She was busy all day with suppressing her complaints in order to survive so that she would not become overwhelmed and cause an emotional outburst of fear or sadness. This constant struggle cost her a tremendous amount of energy. She also suffered from hypersensitivity to stimuli such as sound, temperature or touch. She had many unexplained pain complaints on her right side of her body. The patient also suffered sleep disorder and chronic fatigue. The patient was unable to make friends and had become isolated, even within her own family. Finally, she suffered from the knowledge that there was no prospect of an improvement in her situation.

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2018-27 Male, 70s, ID

For more than five years before death severe, unexplained pain that radiated from the right upper abdomen to the back and legs. He had a psychiatric history associated with unresolved trauma. Fixation on his pain complaints had came to determine his identity to such a degree that a cure was not possible. (…) Cognitive behavioral therapy and psychotherapy were not considered useful because of the patient's limited intelligence. (…) According to [doctor], the great burden of suffering had to be seen in the context of the limited capacity of the patient, which arose from his limited intellect and virtually absent ability to reflect. (…)The physician was convinced that the patient had a psychiatric disorder and that most of his pain experience had a psychological cause. It is possible that the dependent personality structure, his intellectual disability and loneliness also played a significant role in this (…) The patient's suffering consisted of untreatable, continuous, severe pain in abdomen, back and legs that dominated his life. There was a high level of suffering. The patient did not have sufficient coping strategies to deal with his complaints. He was fixated on his pain complaints and as a result became completely socially isolated. He could no longer practice his hobbies, almost did not come more outside and spent most of the day on the couch. His complaints made him gloomy. There was anhedonia. The patient suffered from the hopelessness of his situation, the lack of prospects for improvement and saw no future for him. He longed only for death; in this desire he was also completely fixated.

2018-69 Male, 50s, ID + ASD

Over thirty years before his death, he was diagnosed with schizophrenia or schizotypal personality disorder. A year after this diagnosis was made, it was changed to "borderline state in an autistic, socially isolated, compulsive personality in pre-psychotic male".(…) Diagnostically, there was a grief reaction with both autistic and psychotic traits, in a vulnerable man, in whom overload can also trigger depression.(…) The patient's suffering consisted in the fact that everything was too much for him: the daylight immediately upon waking and all the other actions he had to do all day long. The patient lost names, often could not find his way and had more and more trouble with technical actions. He struggled with nightmares, panic attacks and fits of rage and a strong degree of overstimulation, among other things through interactions with third parties. Following the death of one of his parents, the patient suffered from the greatly increased dependence on caregivers. Due to his inflexible and compulsive way of managing his life, he could not adapt to constantly changing people in his environment. He experienced constant stress and lost his overview of daily life. Panic and despair were constantly lurking. The patient felt incapable of functioning on any level in today's society and was not the person he wanted to be, with a job and a family. He also suffered from bowel complaints, which increased his suffering.

2019-126 Male, 20s, ASD

Known with impulse regulation problems and behavioural problems since his early teens.(…) was diagnosed with borderline personality disorder with antisocial features eight years before death. In addition, an obsessive compulsive disorder, pyromania, substance abuse and ADHD with ASD features were identified. There was also presumed to be a brain injury. (…) The patient's suffering consisted of an uncontrollable urge to act impulsively such as pyromania, acting out and self-harm, to cut out rising inner tension. Thoughts of arson and self-harm kept him busy all day. He could

hardly suppress those thoughts and therefore constantly damaged himself. The patient knew that because of his disorders could never function normally in society. He therefore experienced his future as unliveable.

2020-11 Female, 30s, ASD

Had frequently felt unsafe and vulnerable in her youth and had been sexually abused for a period of one year as a young adolescent. She had been under mental health treatment since early childhood due to multiple problems. The patient was diagnosed with post-traumaic stress disorder (PTSD), borderline personality disorder, and autism spectrum disorder (ASD) .(…) The core of her suffering was that she could not love herself. She suffered from anxiety, had a very low stress tolerance and quickly became overstimulated and panicked. She could barely shape her own life independently. There was compulsive worrying and an agonizing perfectionism. The patient experienced flashbacks and nightmares of the abuse. (…) The patient continued to struggle with an extremely negative self-esteem, fears and panic, hypersensitivity to stimuli, problems with dealing with emotions, difficulties in establishing and maintaining relationships, and the difficulty of everyday life. (…) The patient had felt unhappy since childhood. She couldn't love herself and was constantly judging herself. She struggled with feelings of fear and panic and suffered from reliving the abuse in her youth, with images during the day and nightmares in dreams at night. The patient slept poorly and felt very tired. She was unable to do her housework for cook for herself, establish relationships, and keep work.

2020-150 Male, 40s, ASD

The patient was diagnosed with Autism Spectrum Disorder (ASD) and Obsessive Compulsive Disorder (OCD) eight years and six years prior to death. Both disorders had been present since childhood. In addition, the patient had severe emotional regulation since childhood problems, which by adulthood had been diagnosed as a broad cluster B (borderline, narcissistic, theatrical) personality disorder. In addition, the patient had suffered from acquired brain injury and epilepsy since one year before death. There was also substance abuse. The patient's suffering consisted of continuous feelings of fear. The fear manifests itself in a fear of contamination and serious compulsions. The patient had the feeling that he did not understand the world, but also felt strongly that the world did not accept him. He tried to suppress his fears with excessive use of alcohol and other narcotics. His behavior drove everyone away from him.(…) The consultant found that the patient mainly suffered from anxiety, compulsive complaints and loneliness due to the limitations that arose from ASD, OCD, acquired brain injury, and personality disorder.

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4. Main cause of suffering: ASD/ID + Somatic + Mental Health

- ASD/ID as one of the main causes of suffering in itself, along with both somatic mental health problems

2020-133 Female, 20s, ASD

Had suffered from a chronic fatigue syndrome, also referred to as somatic symptom disorder, for three years before death. The patient also had symptoms since childhood, with aggravation from young adulthood that were classified as obsessive-compulsive disorder (anxiety disorder) 16 years before death. From childhood, the patient also experienced complaints of a diagnosed dissociative disorder/depersonalization and derealization that were diagnosed four years before death. Furthermore, the patient was diagnosed with autism two years before her death, a disorder from which she has experienced negative consequences since her early years (…) The patient suffered excruciatingly as a result of compulsions, fears, nightmares, fear of contamination, autoimmunity and extreme fatigue. She stayed in bed 22 out of 24 hours. Except for contact with friends, especially via whatsapp, she had no social life.

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5. Main cause of suffering: Mental Health

2013-22 Female, 70s, ID

The patient's suffering consisted of an increase in her perceptions that people in her immediate environment were influencing her life and that they made life impossible for her, and from increasing agitation and exhaustion. She suffered from the dependence on the care of others and the fact that she was not in control of her own impulses and that her emotions controlled her life (…) During the last two years of treatment, the patient had repeatedly and consistently expressed that she did not want to live any longer, given her impaired vision, the fact that she had been treated in psychiatry from an early age and all therapy had no effect on her mood swings, her difficulty in contacting others and the inconvenience she experienced from the experiences she had (that lights shone through the window in the night, making her alternately very anxious and furious). She repeatedly indicated that this was no life for her.

2019-109 Female, 40s, ID

Complex post-traumatic stress disorder (PTSD), recurrent depressive episodes and borderline personality. There was also conversion. The disorders arose mainly from abuse and affective neglect in childhood.(…) The patient's suffering consisted of the fact that she experienced her life as hell. She felt old and exhausted. She suffered from traumatic flashbacks. Her mobility decreased. She also suffered from the fear of becoming demented, like her mother.

2019-20 Male, 40s, ASD

Had suffered from psychological complaints, mainly depression, for about twenty years before death. In addition, over the years, the diagnosis of borderline and later the diagnosis of autism. In addition, the patient had an alcohol problem.(…) The patient's suffering consisted of pain and sorrow, which he experienced throughout the day. He felt lonely and barely got out the door. He felt empty and numb. He was also rebellious, shouted and cried a lot. As a result of the ECT treatments, there was of memory loss.(…) The patient suffered the most from the depressive symptoms, so that psychotherapy for the personality problem did not lead to would lead to a substantial improvement. The alcohol problem was secondary to the depression and the personality problem.

2020-126 Female, 30s, ASD

Entered care about twelve years before death due to persistent sadness, suicidal tendencies and automulation. Three years later, a type II bipolar disorder in cluster C personality problem was diagnosed. (…) Ultimately, a recurrent major depressive disorder without psychotic features and an avoidant personality disorder diagnosed. About two years before death, the diagnosis of Autism Spectrum Disorder (ASD) was also made. The patient had an almost continuous negative sense of seeing, feeling and experiencing things and the urge to harm herself. She felt didn't feel valued or at ease in virtually any relationship or situation. Every day was a new challenge to get through. She suffered from the lack of perspective on a meaningful existence for her.

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2020-136 Female, 30s, ASD

Suffered from an anxiety disorder since early childhood and later developed severe obsessive compulsive disorder (OCD). In adolescence an Autism Spectrum Disorder (ASD) was diagnosed. In adulthood, a personality disorder (cluster B and C features), a psychotic disorder NAO with threatening aggressive behavior towards environment and Tourette's Syndrome were diagnosed. The patient experienced many periods of sadness in her life, which were reactive to the burdensome OCD symptoms. She repeatedly attempted suicide.(…) The patient's suffering consisted of continuous intrusive thoughts and compulsions. She often felt lonely and sad. The patient described her life as a succession of misery, ignorance, doubt and struggle. This completely exhausted her and the patient felt desperate.

2020-53 Female, 60s, ID

The patient's suffering consisted of constant depressive thoughts and feelings of tension and anxiety. When stress increased, there was self-harm. She had frequent panic attacks. The patient had chronic suicidal thoughts. She slept badly and couldn't enjoy anything anymore. The patient just wanted to die.

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6. Main cause of suffering: Somatic

(Note: all of these are patients with ID)

2013-51 Female, 60s, ID

Main cause of suffering: Somatic (Multiple)

Infantile encephalopathy, COPD GOLD IV, heart failure, a pathological vertebral fracture, a stroke and TIAs (…) The patient's suffering consisted of limited mobility, severe fatigue, hard-to-cut fits of breathlessness, real fear of dying from swallowing, drug side effects, tendency to fall, dysarthria, pain, palpitations, fear of suffering lay ahead and the hopelessness of her situation. The patient spent a lot of time in bed. She was on oxygen. The patient was no longer able to engage in the activities she enjoyed. Due to her situation, the patient became increasingly care dependent. She thought this was terrible. She absolutely did not want to become a vegetable.

2016-03 Male, 30s, ID

Terminal illness

The patient was diagnosed with tuberous sclerosis in early childhood. Over the years, angiomyolipomas developed in a kidney, rhabdomyomas in the heart, pancreas, skin and brain, and he had epilepsy. As a result of the condition, he had an intellectual disability. In the years before death, liver metastases were found and progressive tumor growth was seen in the abdomen. About nine months before death, patient decided to stop further investigations (…) The patient's suffering consisted of pain, nausea, inability to sleep, fatigue and exhaustion. The patient was able to less and less because of the fatigue. He had become bedridden and dependent on the care of others. He suffered at the prospect of dying with extreme nausea or pain due to a bleeding in the abdomen or an epileptic fit without being able to say goodbye to those around him, and he suffered from the hopelessness of his situation.

2018-71 Male, 50s, ID

Had been known with various ailments for quite some time. First, he suffered from type 1 diabetes mellitus. Over time, he developed several complications, including neuropathy, reinopathy, and nephropathy. He also had charcot feet and macro- and microvascular disorders in the legs, as well as Raynaud's phenomenon and rheumatoid arthritis. In addition, he had several myocardial infarctions. In addition, there was an obstructive sleep apnea syndrome and recurrent urinary problems with infections and sepsis (…) The patient's suffering consisted of chronic pain complaints and the debilitating consequences of his conditions. The necessary use of certain drugs disrupted his (already difficult to regulate) blood sugar level, with all the consequences that brings, such as emergency admissions in hospitals. He also frequently had non-healing wounds and ulcers on his legs and was deformed feet. For this reason, several toes were amputated. The patient had difficulty moving around and was dependent on the outside of the home of a scooter. He was forced to spend most of his days lying down. He was no longer able to carry out activities that made his life meaningful. Moreover, he was in social isolation. He suffered from the forced inactivity, the dependence on care

and the hopelessness of his situation. Patient absolutely did not want to be admitted to a healthcare institution. He experienced a low quality of life.

2019-94 Male, 70s, ID

Terminal illness

Diagnosed with Parkinson's disease five years before death. At that time, the disease was already at a fairly advanced stage.(…) The patient's suffering consisted of difficulty in swallowing with excessive salivation. As a result of choking, he developed pneumonia twice. There was a severe stiffening that made him immobile. He was incontinent and had painful contractures in his wrists and elbows. The patient was a mentally retarded man (IQ 80) who, up to three months before his death, lived his life as well as possible with cheerfulness and humor. In the end, his behavior changed. He was fearful, threw things, called names and hit people. Medicine did not help for this. He suffered from complete dependence and lack of perspective on improving his situation.

2020-15 Female, 30s, ID

Diagnosed with a brain tumor as a toddler. The patient was operated on and underwent radiotherapy. In her youth she had a recurrence, for which the patient underwent radiotherapy again.(…) Over the years, there has been an increase in the patient's complaints. These complaints consisted of loss of strength of the arms and legs, pain, loss of vision, wounds on the thorax, voice problems, sensory disturbances in the legs, fatigue and lack of appetite. Some of these complaints could not be explained because the brain tumor was shown to be stationary. The last 10 years before the death, the patient lived in a nursing home. (…) The patient had become very tired, bedridden and wheelchair dependent. She was no longer able to pursue her hobbies and could no longer be the zestful person she wanted to be. She suffered from this physical decline, the hopelessness of her situation (…) She had increasing pain in the head and limbs, a paresis of her left arm, loss of strength and sensory disturbances in the legs. In addition, the patient was very tired and there was loss of condition. The patient had become bedridden and wheelchair dependent. She suffered from increasing dependence, the inability to carry out the activities important to her and the inability to be the person she once was and wanted to be.

2020-54 40s Male, ID

In the written explanation, the doctor emphasized that the patient's main complaints, namely pain, gait disturbances, urinary incontinence and alvi, were probably caused by Recklinghausen's disease. He also mentioned that learning and behavioral disorders and reduced intelligence are also described as regularly occurring in neurofibromatosis type 1. There were indications that the patient also suffered from this, which manifested itself in a lack of overview, a somewhat childish use of language and slow responsiveness.

The documents show that the doctor was convinced at that time that the patient's suffering was not caused by a psychiatric disorder

Tuffrey-Wijne I, Curfs L, Hollins S, Finlay I (2023). Data set to accompany the study "Euthanasia and physician-assisted suicide in people with intellectual disabilities and/or autism spectrum disorders: an investigation of 39 Dutch case reports (2012-2021)". Case numbers: Full cases to be found on https://www.euthanasiecommissie.nl/ (in Dutch). This document contains extracts from each case (translated into English), with the authors' categorisation

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7. Main cause of suffering: Somatic + Mental Health

2014-83 Female, 50s, ID

There was a persistent personality problem [and multisocial problems] and severely disabling somatic problems (…) The patient was paranoid and anxious, dependent and egocentric. Three years later she underwent a lower leg amputation due to vascular problems/diabetes. (…) The patient's suffering consisted of phantom pain, chronic abdominal pain and chronic chest pain. There was a pressure ulcer, from which she also experienced pain, and from chronic diarrhea. The patient suffered from her disability and wheelchair dependence. she couldn't read anymore or enjoy anything. Because of her personality she came into constant conflict with her environment. Her family had been driven apart by this. Her personality also meant that she needed constant guidance, direction and care, so that she was forced to live in a gerontopsychiatric ward. The patient had no control over her life and felt, socially speaking, left out. She suffered from the hopelessness of her situation and the meaninglessness of her life.

2016-73 Female, 70s, ID

Both somatic and psychiatric problems. She had been suffering from COPD for two years before her death (…) Because of her weakness, she had the tendency to fall, which she found scary. The patient didn't want to break anything. She constantly had the feeling that she had to pass urine and she was incontinent, which she was ashamed of. She also suffered from shingles. As a result of the gonarthrosis and osteoporosis the patient had chronic pain that was treatment resistant. She was also restricted in her freedom of movement. The patient was a nature person and liked to go outside, but that was no longer possible. She was almost bedridden and could barely walk. By lying down, bedsores developed. The patient suffered not only from her physical situation, but also from the psychiatric problem she faced. Due to the increase in her physical problems, she no longer experienced any coping capacity ("draagkracht"). It was increasingly difficult to avoid her traumatic past. The patient kept thinking about it and thought it was terrible. She suffered from nightmares and medication to improve her sleep did not work well enough. She did not want to increase the medication, because she didn't want to walk around like a zombie. And she sensed that talking and long-term contacts with psychiatry would only make the suffering worse. The patient, who had always been strong, was now done ("op") and didn't want anything anymore.(…) The patient had limited coping strategies.

2020-113 Female, 50s, ID

Suffered from spina bifida aperta, at low thoracic level. There was total paralysis of her lower body hemisphere. (…) Patient's IQ was 65, conforming with mild intellectual disability. There was also osteoarthritis, spondylosis and kyphosis. The patient also struggled with chronic pressure ulcers in the sacrum, renal dysfunction, tinnitus, tension headache, muscle atrophy and pain at her elbows, upper arms and shoulders. She was wheelchair-bound and lived in a care facility. In her youth, the patient had been affectively and emotionally neglected and she had often felt unwanted, unsafe and vulnerable. Because of this, there was a disturbed social-emotional development. In her adult life she had to change her living environment, support workers and caregivers very frequently, which

has demanded a lot from her adaptability. The patient felt damaged by life. She had always felt rejected, she no longer had faith in humanity. She experienced her total dependence as an unbearable burden. She increasingly suffered from the physical effects of her infirmities, especially the pain in her arms and shoulders. She had no contacts or day-to-day activities that were meaningful to her. The patient didn't want to have to live like this anymore.