



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

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Submission Cover Sheet

End of Life Choices in the ACT

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Submission

on

End of Life Choices

to the

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1. Introduction

On 30 November 2017, the ACT Legislative Assembly established a Select Committee to review and report on end of life choices in the ACT.

The Committee is required to conduct its inquiry and report to the Legislative Assembly on or before the last sitting day in 2018 (29 November 2018).

FamilyVoice Australia is a national Christian voice – promoting true family values for the benefit of all Australians. Our vision is to see strong families at the heart of a healthy society: where marriage is honoured, human life is respected, families can flourish, Australia’s Christian heritage is valued, and fundamental freedoms are enjoyed.

We work with people from all mainstream Christian denominations. We engage with parliamentarians of all political persuasions and are independent of all political parties. Submissions close 23 February 2018.

2. Terms of reference

The Committee’s full terms of reference are to inquire into and report on:

- (a) current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life, including palliative care;
- (b) ACT community views on the desirability of voluntary assisted dying being legislated in the ACT;
- (c) risks to individuals and the community associated with voluntary assisted dying and whether and how these can be managed;
- (d) the applicability of voluntary assisted dying schemes operating in other jurisdictions to the ACT, particularly the Victorian scheme;
- (e) the impact of Federal legislation on the ACT determining its own policy on voluntary assisted dying and the process for achieving change; and
- (f) any other relevant matter.

3. Overview

The practice of medicine is an ancient profession that, from its earliest references in recorded history, has worked to define the moral and ethical boundaries within which it operates, to protect both patients and medical practitioners. The Hippocratic Oath included this insistence: “I will give no deadly medicine to anyone if asked nor suggest such counsel.” This Oath has informed medical ethics since the fifth century BC.¹

After the unspeakable evils performed by Nazi doctors prior to and during the second World War, the Declaration of Geneva was drafted in 1948 in response to such crimes. It stated, “I will maintain the utmost respect for human life from the time of conception.” A year later, the International Code of Medical Ethics insisted that “a doctor must always bear in mind the obligation of preserving human life from the time of conception until death.”²

The World Medical Association adopted the Statement of Marbella in 1992. They reaffirmed it as recently as 2015. It says this:

*Physician-assisted suicide, like euthanasia, is unethical and must be condemned by the medical profession. Where the assistance of the physician is intentionally and deliberately directed at enabling an individual to end his or her own life, the physician acts unethically.*³

The Australian Medical Association’s recently updated position statement on End of Life Care asserts: “the core message ... is that there needs to be much greater investment in quality end of life care, especially nationally consistent palliative care services.” The AMA maintains its position that doctors should have no place in medical interventions where the ‘primary intention’ is the termination of human life.

4. End of Life Care

The ACT government has the opportunity to demonstrate its care for the inherent dignity and worth of all human beings, regardless of their physical capabilities, by further developing and reinforcing a world-class ‘end of life care’ system.

Currently under Australian Law, every adult person has the following rights:

- They may decide what is done (or not done) to their bodies; lawful medical treatment requires consent, with the exception of emergency cases;
- Where a person does not possess this capacity, there are three ways in which a decision can be made on their behalf:
 - Via an Advance Directive, made prior to their incapacity and expressing the person’s wishes in relation to their treatment;
 - A substitute decision-maker can make the decision, generally based on what they believe the person would have wanted and their best interests; or
 - A Tribunal or the Supreme Court can provide consent or make a treatment decision.⁴

Dr John Buchanan, a consultant psychiatrist and former palliative care medical specialist, has identified the following issues in relation to assisting patients in end of life decision making:

- Medical staff are confused about the goals of patient care (is it cure or palliation?) especially in hospitals, sometimes leading to inappropriate use of acute medical treatment (resuscitation) in some terminally ill patients, when usually what is required in is the goal of symptom control only;
- Confusion of goals in palliative care: the appeal of assisted suicide grows if there is failure to apply the correct goal of hospital care, which gives rise to fear in some patients;

- There is poor understanding and application of palliative care principles by many medical and nursing staff who do not work in formal palliative care services;
- There is poor community understanding of palliative care treatment and distorted beliefs about terminal symptoms which can lead to elevated fears of medical care.⁵

ACT government policy needs to focus on improving education of all medical and nursing staff as to the importance of clarification of the **goal** of care for all patients, whether this is curing the illness, or instead the palliative relief of symptoms:

- **‘Goal of care’** should be ascertained through conversations with patients and families, and recorded in patient histories, working to ‘prevent the inappropriate and unwanted use of technology which a person may explicitly reject’;
- better palliative care knowledge for all medical staff (not just bigger formal palliative care services), so means of control of distressing symptoms is better understood;

Advance Care Directives can improve end of life care, ameliorate stress and anxiety, and gratify patients and families, but they have limitations. Also, the use of Advance Care Directives is currently limited.

Dr Buchanan made the following recommendations to the Victorian inquiry into End of Life Care; they offer experienced clinical insight and warrant listing/repeating here:⁶

Recommendation 1: That knowledge about palliative care which is already available amongst specialized medical and nursing practitioners is made more broadly available; that the government encourage the expansion of palliative care principles further into general medicine.

Recommendation 2: That medical staff be required to clarify ‘goal of care’ with relatives of all admitted patients, at time of admission; that this become part of standard admission procedure.

Recommendation 3: That a public education campaign around Advance Care Directives be undertaken to raise public awareness; that the language of ACDs be clarified to focus on goal of treatment, such as cure or palliative symptom control and the circumstances in which an ACD applies, as opposed to a focus on refusal of treatment.

5. Palliative Care

The World Health Organisation defines palliative care as follows:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- *provides relief from pain and other distressing symptoms;*

- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death;*
- *integrates the psychological and spiritual aspects of patient care;*
- *offers a support system to help patients live as actively as possible until death;*
- *offers a support system to help the family cope during the patients illness and in their own bereavement;*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
- *will enhance quality of life, and may also positively influence the course of illness;*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.⁷*

This definition has been adopted by Palliative Care Australia.⁸ Palliative Care Australia is an incorporated body whose members are the eight State and Territory palliative care associations and the Australian and New Zealand Society of Palliative Medicine. The membership of those associations includes palliative care service providers, clinicians, allied health professionals, academics, consumers and members of the general community.

All the elements of this definition are important in considering the provision of palliative care in Australia.

Palliative care is not limited to pain control. It also addresses other distressing symptoms, including physical symptoms such as nausea and incontinence, as well as psychological, social and spiritual matters.

Palliative care takes into account the patient's family as well as the patient. It focuses on the need to provide support systems both "*to help patients live as actively as possible until death*" and "*to help the family cope during the patient's illness and in their own bereavement*".

The last bullet point in the definition makes it clear that palliative care is not limited to the relief of symptoms only after all therapeutic interventions have failed, but should be initiated in conjunction with therapeutic interventions.

Recommendation 4: The provision of palliative care in the ACT should take into account all the elements of palliative care as defined by the World Health Organisation, to ensure a broad and comprehensive approach to the funding and provision of palliative care.

5.1. Ensuring provision of quality palliative care services

All jurisdictions across Australia are facing significant challenges and gaps that exist within current health systems, including patients accessing the form of care they choose.⁹ These include:

- An increasing demand for end-of-life care;
- Changing patterns of disease, with an increasing number of people having complex health needs and dying from a range of co-morbidities;
- The unpredictable nature of non-cancer diseases, which contribute to patients with dementia, frailty and/or multi-organ failure receiving less than optimal care;
- Lack of adequate coordination and continuity of care across health settings;
- The number of patients that are admitted to acute hospitals at end-of-life, many of whom die in hospital despite expressing a wish to die at home;
- Clinicians' ability to recognise and respond to clinical deterioration, discuss patients' goals of care and engage in open and honest conversations;
- Greater recognition of the role of Specialist Palliative Care teams, including appropriate and timely referral;
- The need for community awareness and understanding of death, dying, loss, palliative and end-of-life care and to recognise the limits of medical interventions.¹⁰

The Victorian Auditor-General's April 2015 report into palliative care found that:

- Demand for home-based care is increasing and some metropolitan community palliative care services have struggled to meet this demand, resulting in waiting lists to access services. This can place additional stress on patients and carers, and can mean that some people who have chosen to die at home cannot spend their last days there;
- More also needs to be done to support carers and families. Improving respite provision and access to psychosocial support remain major priorities. Notably, 'support for carers' and 'engaging with the community' were two key priorities that continue to require attention;
- Clear expectations for service delivery across the state that provides sufficient and appropriate funding to health services and community organisations is needed.¹¹

A recent Audit Office report found that NSW Health's approach to planning and evaluating palliative care is not effectively coordinated and that some services are poorly managed.¹²

The ACT system is experiencing similar challenges, particularly in relation to accessing information around end of life care.¹³ It is imperative that these findings be followed by practical support to meet growing demand.

Recommendation: That ACT palliative care services receive greater funding and structural support to meet current and expected future demand; and, in palliative care service provision, greater consideration should be given to home-based care and to the needs of carers and families.

6. Euthanasia and assisted suicide

6.1. Definitions

Some confusion surrounding end-of-life issues is caused by a misunderstanding of definitions. The Australian Medical Association (AMA) provides the following explanations of euthanasia and assisted suicide:

Euthanasia is the act of deliberately ending the life of a patient for the purpose of ending intolerable pain and/or suffering;

Physician assisted suicide is where the assistance of the medical practitioner is intentionally directed at enabling an individual to end his or her own life.¹⁴

Euthanasia and assisted suicide are, therefore, the intentional ending of a life (to put it baldly, killing a patient) and should not be confused with medical end-of-life considerations. The AMA provides some points of clarification:

The following forms of management at the end of life **do not** constitute euthanasia or physician assisted suicide:

- *not initiating life-prolonging measures;*
- *not continuing life-prolonging measures;*
- *the administration of treatment or other action intended to relieve symptoms which may have a secondary consequence of hastening death.¹⁵*

6.2. Issues

6.2.1. Culture change

If laws were changed to allow euthanasia or assisted suicide, it is likely that medical training would need to include courses on how to kill patients, or counsel them how to take their own lives. Doctors would then be equipped to treat or kill their patients, affecting the doctor-patient relationship.¹⁶ This would destroy the bond of trust between doctor and patient. It would also effectively alter the culture of the medical profession itself, from one focused on the preservation of life, to a culture that permits suicide or the killing of patients. Making the taking of human life a part of medical ‘treatment’ changes the way doctors manage illness, and allows the possibility of taking the life of any individual perceived to be suffering, even without the use of conventional treatments.

6.2.2. Individual autonomy vs common good

The need for autonomy in decision making has often been put forward as a major pillar supporting the case for euthanasia and assisted suicide. It places most emphasis on the individual and opposes

arguments around the sanctity of human life. But autonomy of the individual should never have primary consideration in decisions where changes to law affect entire communities (see decision by Scottish Parliament, under ‘other jurisdictions’). In other words, the place of individual choice should always remain secondary to protection and wellbeing of society at large in relation to the enactment of legislation. Legislative change affects all citizens, and law-makers must consider the effects of change upon the whole community, as well as unintended effects on:

- other ill people;
- those with psychiatric illness or disability;
- Practice of medicine in hospitals and aged care communities, as well as the broader community.

6.2.3. Human nature

Despite the so-called compassion of the ‘dying with dignity’ movement, euthanasia risks bringing out the worst in human nature, such as:

- The desire for value for money in the health system warping into a preference for cheap death rather than expensive care;
- The desire of unscrupulous relatives to get their hands on an inheritance or relieve themselves of the burden of caring for someone;
- The desire of relatives to end their own suffering caused by seeing their loved one in distress;
- The implicit message that creeps into our culture that terminally ill people are a burden and should remove themselves. As Dying with Dignity admits, fear of being a burden is cited in 40-59% of assisted dying requests in Oregon and Washington.¹⁷

6.2.4. Slippery slope

Proponents of euthanasia and assisted suicide claim that ‘the law you enact is the law you get’.¹

However, once we allow doctors to deliberately cause the death of certain patients, it becomes harder to argue that others who might want a medically supervised death should not also be allowed one.

Risks associated with the legalisation of assisted suicide or euthanasia are high, and in practice have given rise to significant concerns, including:

- The illusory nature of safeguards;¹⁸
- Extensions of criteria, including euthanasia without request;
- Extension to include those with mental illness, particularly those with depression;
- Euthanasia of those who are not terminally ill.

In a number of jurisdictions around the world, the interpretation of euthanasia and assisted suicide laws have been relaxed to include all of the above. Despite considerable effort to ensure safety protocols and guidelines, these have proven illusory and impossible:

¹ A slogan promoted by Dying with Dignity NSW, *Assisted dying: Setting the record straight*, page 6.

- In the Netherlands, the euthanasia law has not changed but its interpretation has been altered. As a culture of death became more accepted, the interpretation of ‘unbearable suffering’ has been broadened to include mental as well as physical anguish;
- The experience in the Netherlands and Belgium shows clearly that a consequence of assisted suicide legislation is extension of the criteria to include non-voluntary euthanasia, non-terminally-ill people, and people with psychiatric illness;¹⁹
- Children can access euthanasia from age 12 and parental consent is not needed beyond age 16;
- Most chillingly, the Groningen Protocol for severely ill newborn babies (infanticide) has entered into Dutch medical practice without the involvement of Parliament.²⁰

In an appearance before the Scottish Parliamentary inquiry into assisted dying, Dr Peter Saunders of the organization *Care Not Killing* summarized the shift thus:

In the US states of Oregon and Washington, in Belgium and in the Netherlands, we see three key things. The first is an annual increment in the number of cases. For voluntary euthanasia cases in the Netherlands, it has been 10 to 20 per cent a year since 2006. The second thing is a widening of the scope. It starts with the terminally ill, and then it is the chronically ill. It starts with adults, and now in Belgium it is children. It starts with the mentally competent and it then shifts to the mentally incompetent—those with dementia. The third thing, and probably the most worrying of all, is that as time goes on we see a change in the public conscience and the medical conscience. That does not worry some people, but it worries me a lot that the public conscience changes so that people come to accept situations that, 10 or 20 years ago, they would have found intolerable.²¹

The following list is far from exhaustive, but provides some examples as to why euthanasia and assisted suicide should be utterly rejected by policymakers.

6.2.5. Pressure on vulnerable people

There is now significant data showing that patients **do not** primarily seek euthanasia or physician assisted suicide because of inadequate pain control. Dr Ezekiel Emanuel reported these important findings recently in *the Medical Journal of Australia*:

If not pain, then what motivates patients to request euthanasia and PAS? Depression, hopelessness, being tired of life, loss of control and loss of dignity. These reasons are psychological — they are clearly not physical pain — and are not relieved by increasing the dose of morphine, but by antidepressants and therapy. In the states of Oregon and Washington, the reasons for wanting PAS were: 90% of patients reported loss of autonomy, 90% were less able to engage in activities that make life enjoyable and 70% declared loss of depression and hopelessness are not listed and are not included in the reporting list. Likewise, in the Netherlands, the main legal requirement is “extreme physical or mental suffering,” and patients’ reasons are classified in this manner, making it hard to know whether the reasons are physical symptoms of depression. However, when researchers from the Netherlands — who were convinced that the main rationale was pain — interviewed patients who requested euthanasia, they found that few of the ones using euthanasia were experiencing pain, but most were depressed.²²

Experience in Oregon (US), which has ‘physician-assisted dying’, shows that physical suffering is not the major issue for those requesting physician assisted suicide – but fear of being a burden is:

- Of the 673 people who had died under the provisions of the Act as of 14 January 2013, only 23.5% listed “inadequate pain control or concern about it” as a consideration.²³
- Earlier annual reports noted: “Patients discussing concern about inadequate pain control with their physicians were not necessarily experiencing pain.”²⁴
- By contrast some 38.6% of those who died after taking prescribed lethal medication cited concerns about being a “burden on family, friends/caregivers” as a reason for the request.²⁵

A study published in the *Journal of General Internal Medicine* shows that the majority of people in their study pursued Physician Assisted Suicide for reasons other than pain, such as illness related experiences like tiredness, fear of the future, loss of function and loss of sense of self.²⁶

Euthanasia and assisted suicide seem to be more about relieving other people of a “burden” than relieving unbearable or un-relievable pain.

6.2.6. Mixed messages on suicide

Euthanasia and assisted suicide laws jeopardise the health of those struggling with depression and mental illness.

According to the most recent figures, suicide remains the leading cause of death for Australians aged between 15 and 44.²⁷

- In 2015, there were 3025 deaths due to suicide – and Lifeline estimates that there are also approximately 65,300 suicide attempts each year.
- The suicide rate amongst Aboriginal and Torres Strait Islander peoples is more than double the national rate. In 2015, suicide accounted for 5.2% of all Indigenous deaths compared to 1.8% for non-Indigenous people.²⁸

Not only does consideration of euthanasia and assisted suicide undermine efforts to build better mental health, there have been suggestions the debate is directly linked to a higher instance of youth suicide.

A 2007 article casts light on this connection:

Young Australian men in their prime commit suicide at the rate of nearly 400 per year. In 1997, when the Federal Parliament held a conscience vote on the contentious issue of the Northern Territory's euthanasia legislation, suicide peaked among Australia's 20-24 male population, reaching 40 per 100,000, which is nearly twice the current rate.

As with copy-cat behaviour, merely drawing attention to the supposed right to take one's own life has only encouraged the practice.²⁹

Scholars in the US have also noted that legalising physician assisted suicide has not led to lower suicide rates, but may in fact have increased them.³⁰ Legalisation of euthanasia and assisted suicide creates a

perception that some lives are worth more than others – and that there is a point at which life is no longer worth living. This message must be rejected.

6.2.7. Provision of palliative and psychiatric care

The practice of euthanasia has been found to have serious flaws in terms of patients seeking access to palliative care or psychiatric treatment.

The radical step of ending or taking a life would surely be considered only after all other avenues have been explored – yet the Belgian experience shows this is not the case. Disturbingly, a majority of euthanized patients were not previously visited by a palliative care team.

Barely a fraction of euthanized patients received a visit from a palliative care specialist or a psychiatric consultation, as a 2015 Belgian study documents:

When analysing the latest data provided by the Belgian Federal Euthanasia Commission (years 2012–2013), we see that only 40 percent (1,283 out of 3,239) of the euthanized patients had a visit by a palliative care team, barely 12 percent (396 out of 3,239) had a visit by a palliative care specialist, and just 9 percent (307 out of 3,239) were consulted by a psychiatrist (Commission Fédérale de Contrôle et d'Évaluation de l'Euthanasie 2014). Thus almost 40 percent of the patients who received euthanasia did not see a palliative care specialist nor interacted with a palliative care team.³¹

Given that pain and suffering are frequently-cited arguments in favour of euthanasia, it is concerning that experience shows euthanasia to be a first resort, rather than professional pain management. Likewise, considering the likelihood of depression and other mental health issues in such cases, it is alarming that appropriate care has been supplanted under a euthanasia regime.

6.2.8. Effect on family and friends

There is also a question of the mental wellbeing of others involved in euthanasia and assisted suicide cases.

In Switzerland, a recent study found that about 20 per cent of family members or friends who witnessed an assisted suicide subsequently suffered from full (13 per cent) post-traumatic stress disorder or sub-threshold (6.5 per cent) post-traumatic stress disorder.³²

In short, a significant number of a patients' family and friends are likely to suffer severe stress following the patient's premature death.

6.3. Summary

The list of concerns raised here regarding euthanasia and assisted suicide is far from exhaustive. These particular issues have been highlighted to give an idea of the deleterious effects of such laws.

Whenever lives are deliberately cut short, regardless of the legal framework, there are severe ramifications – not only for patients concerned, but also for family and friends, other vulnerable people, medical professionals, and whole societies.

Recommendation:

Any proposal for euthanasia or assisted suicide should be roundly rejected by policymakers.

7. Other Jurisdictions

Assisted suicide legislation will come into effect in Victoria in 2019, but similar laws were defeated in New South Wales the day before the Victorian laws passed through parliament. Euthanasia or assisted suicide, or both, have now been legalized in a few European countries and US states. Euthanasia laws remain rare because of concerns about protecting vulnerable people and upholding high standards of medical ethics. Euthanasia is legal in Belgium, the Netherlands, Luxembourg, Canada, and Colombia. Assisted suicide (not only by a physician) is legal in Switzerland provided the person has no selfish motives. Physician-assisted suicide is legal in five US states: Oregon, Washington, Montana, Vermont and California.

It has been rejected by:

- England and Wales in 2015
- Scotland in 2015
- Australia, most recently in South Australia, Tasmania and New South Wales in 2017
- Most American states – bills were introduced in 34 states over last decade and the vast majority were defeated.

The key argument that changing the law would open up vulnerable people to exploitation and abuse has so far held sway with politicians around the world. In the United States, the main issue now revolves around medical insurance, as companies have offered to pay for someone's death, but refused to pay for more expensive, ongoing treatment. Since the beginning of 2017, 23 states, with an 'unusual bipartisan consensus', have rejected bills to allow euthanasia and assisted suicide for this reason.³³

The British Medical Association opposes euthanasia and all forms of assisted dying. It believes that ongoing improvement in palliative care allows patients to die with dignity.

Its reasons for opposition are:

- Permitting assisted dying for some could put vulnerable people at risk of harm.
- Such a change would be contrary to the ethics of clinical practice, as the principal purpose of medicine is to improve patients' quality of life, not to foreshorten it.

- Legalizing assisted dying could weaken society's prohibition on killing and undermine the safeguards against non-voluntary euthanasia. Society could embark on a 'slippery slope' with undesirable consequences.
- For most patients, effective and high quality palliative care can effectively alleviate distressing symptoms associated with the dying process and allay patients' fears.
- Only a minority of people want to end their lives. The rules for the majority should not be changed to accommodate a small group.³⁴

The Scottish Parliament recently rejected the *Assisted Suicide Bill*. The committee leading the inquiry acknowledged the following:

- The principle of respect for autonomy is a qualified principle which is usually limited by the rights of others, by public safety considerations, and by the need to consider other principles and values; the argument that the principle of respect for autonomy on its own requires the legalization of assisted suicide *is not* persuasive;
- The British Medical Association itself stated that there is no way to guarantee the absence of coercion in the context of assisted suicide;
- There appears to be a contradiction between a policy objective of preventing suicide, on the one hand, and on the other, legislation which would provide for some suicides to be assisted and facilitated. There is potential not only to undermine the general suicide prevention message by softening cultural perceptions of suicide at the perimeters, but also to communicate an offensive message to certain members of our community (many of whom may be particularly vulnerable) that society would regard it as 'reasonable', rather than tragic, if they wished to end their lives.
- Laws must continue to provide an effective deterrent against abuse, and to be responsive to the individual facts of particular cases.³⁵

8. Conclusion

The term "end of life choices" encompasses a broad swathe of issues, of which this submission has addressed only a limited scope.

There is considerable pressure on the health system, particularly when it comes to services such as palliative care. With demand set to soar over coming decades, it is vital that greater resources be planned for and allocated – and a better diversification of services be included.

Good physical and mental health outcomes must centre on a desire to uphold the dignity and worth of patients – and it is for this reason that policymakers should resist any proposal to countenance euthanasia or assisted suicide. These are not forms of medical care and are fraught with unintended consequences.

Changing the law to allow for assisted suicide or euthanasia cannot improve clinical care, where the main issue is actually poor communication and a poor knowledge of palliative care. Improving standard palliative care in regular medical practice is the best way forward.

Solutions must be found that ensure the common good; the issues which accompany euthanasia and assisted suicide affect the community as a whole, not just those wanting to put an end to their suffering. Killing or taking life as a form of medical treatment would alter the entire culture of medical care in the ACT, to the detriment of all patients who use the medical system, and the doctors who practice within it.

9. Endnotes

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