Should pressure ulcer prevention be part of end of life care?

TRUDIE YOUNG
Director of Education and Training, Welsh Wound Innovation Centre

CONTRIBUTORS
LAUREN JAMES **(LJ)**
Clinical Nurse Specialist, Department of Palliative Medicine, Velindre Cancer Centre

LYNN CORNISH **(LC)**
Tissue Viability Lead, St. Margaret's Hospice Somerset

NICOLA DUFFY **(ND)**
Quality Lead CSW, Public Health Wales

ELLIE LINDSAY **(ETL)**
OBE FQNI, Life President, The Lindsay Leg Club Foundation

Historically there has been an association between the end of life and pressure ulceration. In 1877 Jean-Marie Charcot (more famous for his association with the Charcot foot) noted that patients who were dying developed pressure damage and termed the ulceration 'decubitous ominosus.' Some 29 years later Dr Alois Alzeimher noted that the first patient he diagnosed as having Alzheimer's disease died of sepsis from an infected pressure ulcer (PU). In 1989 following a retrospective review of case notes of patients who developed PUs, Kennedy described the phenomenon of The Kennedy Terminal Ulcer. The rationale came from the fact that over 50% of individuals were dead within six weeks of developing the pressure damage. The clinical description of the Kennedy Terminal Ulcer was similar to that used by Charcot, a butterfly shaped ulcer seen in the sacral area, with Kennedy adding that they were sudden in onset and deteriorated rapidly before death (Sibbald, et al 2009). The term Kennedy Terminal Ulcer has been reviewed in England, the result being that pressure damage at the end of life is categorised using the European Pressure Ulcer Advisory Panel (EPUAP), National Pressure Injury Advisory Panel (NPIAP), Pan Pacific Pressure Injury Alliance (PPPIA) 2019 system and not as a Kennedy Terminal Ulcer (EPUAP, NPIAP, PPPIA 2019; NHS Improvement 2018).

One of the first documents to acknowledge skin failure was the Skin Changes At Life's End (SCALE) document, due to the lack of empirical evidence the document was produced using a three phased Delphi method with a panel of 69 experts (Sibbald et al, 2009). Before this unfortunately it had sometimes been presumed that the development of PUs at the EoL was in part due to a deficit in nursing care, with staff experiencing guilt if a patient developed pressure damage before death. The SCALE document highlighted the failure of the individual's physiological processes to support the skin at the end of life with the blood supply diverted from the skin to the vital organs. This is confounded by the associated fatigue, anaemia, hypoxia and cachexia and immune suppression caused by anticancer medication. However, end of life is not solely associated with cancer as there are many end of life situations caused by other comorbidities.

The World Health Organisation (2020) defines palliative care as 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.

The International Pressure Ulcer Prevention and Management Guidelines (2019) have included individuals receiving palliative care as a special population within the document. It supports the use of the SCALE document and states that at theEoL individuals will lack the physiological resources required to heal pressure damage along with the skin being one of the first organs to be compromised and eventually fail. The document also acknowledges that individuals at the end of life may prefer a single position of comfort with pain being a real issue for these individuals.

Within the cancer care environment individuals display many of the PU risk factors i.e. reduced mobility, nutrition and hydration, an increase in moisture due to urine, faeces and perspiration and the invasiveness of medical devices. Therefore individuals who are approaching the end of their life are at high risk of developing pressure damage; interventions to ameliorate the risk are an important part of the individual's care. However the SCALE document states that pressure damage at the end of life may be unavoidable even with appropriate interventions and optimal care, due to the compromise of the skin and is part of the dying process (Sibbald et al, 2009).

The situation may be compromised even further by an individual's lack of capacity during the dying process and the potential conflict of interest between what the individual is able verbalise compared with the aspirations of their carers.
Trudie Young

1. How do you decide when an individual is at the end of life?

LJ: I think they key word in this is 'individual', as there is not always a one size fits all criteria for making this assessment. The first thing I would be considering is the patient's rate of deterioration, we tend to assess this using the basic trajectory that, if a patient has been deteriorating week to week, then they likely have a prognosis or weeks, if they have been deteriorating day to day then then likely have a prognosis of days and hour to hour then they are likely in the last hours of life. However, this can fluctuate and a patient can suddenly deteriorate very rapidly and enter the last hours phase without progressing through the other stages or a patient may deteriorate (either rapidly or slowly) and then their condition could stabilise and either improve or plateau. This means we have to be very flexible with our assessments and sometimes consider that although we might be in one place at one point in the day that could potentially change very quickly.

We would be considering reversible causes for the deterioration like infection or deranged electrolytes, whether or not it was appropriate to address these or what the patient's wishes were. This is why we try to ensure patients have conversations about ceilings of treatment while they are still able to. I think the main thing we rely upon when making this assessment is experience of EoL care and using that to look at the whole picture of what is happening with that patient. It is about what is best for that person and focusing on what we can do, rather than what is not going to be in their best interest. For example making sure they have adequate symptom control via the most appropriate and least invasive route.

'End of life' is also open to interpretation and different areas and teams might use the terms palliative/end of life/last days of life interchangeably. So it is important to establish how the term is being used and what is understood by it. When I talk about end of life care, I am referring to the care of a patient in their last days and hours of life.

LC: The General Medical Council advise that a patient is end of life when life expectancy is no greater than 12 months.

Every patient is different, and some patients may have only one or two symptoms, others may have several. Symptoms generally become less well controlled and require increasingly frequent review to ensure that the patient is comfortable and able to maintain an acceptable quality of life.

During the final months/weeks patients may experience:

- Increased weight loss and cachexia
- Weekness/fatigue
- Become increasingly sleepy
- Increased pain
- Nausea/vomiting
- Breathlessness
- Limited ability to perform self-care
- Less communicative
- Feeling hot/cold
- Sore/dry mouth.

During the final days/hours patients may also experience:

- Changes to breathing patterns
- Bowel/bladder problems
- Sudden agitation/confusion
- Loss of consciousness (unresponsive)
- Changes to skin colour
- Increased secretions.

A full assessment is required to ascertain the whole picture of deterioration. Factors including physical symptoms, comorbidities, and any psychosocial factors should all be taken into consideration. Experience in caring for palliative patients enables us to recognise when a patient is end of life, but even then, a patient's death can be unexpected and others may remain in the terminal phase longer than expected.

ND: As an individual approaches end of life certain signs and symptoms are recognisable. There is a noticeable change in the individual's conditions as they deteriorate they become extremely weak, mobility is reduced, preferring to remain in bed and eventually becoming bed bound. The individuals need to socialise, eat or drink becoming less important as they experience extreme sleepiness and drowsiness, slowly slipping into unconsciousness. Though there are some individuals who have phases where they wake and talk before slipping back into unconsciousness. Further signs are changes in a person's breathing pattern, some show signs of confusion, agitation and restless. The individual will experience incontinence due to the loss of control of bladder or bowel function.

ETL: From a personal perspective one undergoes many physical and mental changes due to the nature and progression of the disease and treatments such as chemotherapy. Also, there are different stages of emotional reactions, fear of the unknown, grief, anger and denial followed by learning to adjust to dying while still expressing concerns and seeking reassurance. This process depends on the ability to communicate in the early stage ensuring there are no barriers with the multidisciplinary team regarding the final stages and confronting dying. It is a personal journey for many as those experiencing palliative care need to express their fears and talk about their impending death while many retain hope of new research or cure. While we acknowledge the importance of skin protection and prevention of skin damage, we must also recognise it's the therapeutic interaction and effectiveness of the practitioner and awareness of the daily activities of the sick person and their family that brings solace in the final stage of life. Especially as you see a loved one loss interest in food, fluids and surroundings and unable to communicate during their final hours but needing the reassurance that one would not die alone when the mind slips into a dreamless state. To the individual and their family, they see that as more important to be comfortable and pain free, left undisturbed and their loved one is comfortable rather then being repositioned.

2. What do you recommend when an individual or their carer refuses to be repositioned?

LJ: It is important to explain to the patient, or their carer or loved one, the rationale behind why we reposition people, even when they are dying. I tend to focus on explaining that we are trying to prevent PUs that could cause pain, infection and distress to that person. It does however have to be a collaboration between the health professionals and the patient and their 'team of people'. If the patient is getting very distressed and the prospect of repositioning, it is about exploring why. Perhaps they are in pain and need analgesia, or they have been in pain and have finally got comfortable, perhaps they are just tired. This might mean that analgesia needs to be given before repositioning, with enough time for it to take effect or compromising and waiting an hour or so to allow the patient to rest a bit more. It is also about considering what constitutes repositioning and instead of a disruptive roll onto the patient's opposite side, maybe the compromise could be using the bed controls to change the patient's position or moving the patient's pillows, to redistribute pressure. There is also the option in some cases, to use a rotational mattress that can change a patient position without health professionals intervention.

What is important is to keep the conversation open and consider the patient's capacity to make a decision, their autonomy in directing their own care and their general human rights. If a patient is firmly declining being repositioned at that moment in time then a compromise should be explored. If a patient perhaps does not have capacity but essential care needs to be provided, then a best interest decision might need to be made (if loved ones are present then if might be appropriate to include them in this discussion). Each exchange should be documented to provide a record of interactions and this also ensures when the shift changes over there is a clear record of what has been discussed at each point in the day, which can be very helpful with continuity of care.

LC: Investigate the reasons why, as they may be rectified. Work with the patient and family, they are pivotal in being able to offer optimum care. Negotiate care and encourage carers to assist nurses with maintaining skin integrity. Listen to their concerns and offer all the available solutions.

The importance of maintaining skin integrity should be fully explained to the patient and their family, along with the possible consequences of sustaining tissue damage.

Ensure that the patient has access to all the pressure relieving devices that are appropriate for their care. Mattresses that tilt, or other tilting devices and profile beds can prove invaluable in these instances. Although it must be remembered that equipment is not a replacement for physical skin checks and repositioning.

Perform small micro movements, as opposed to the 30° tilt position and consider the use of prophylactic dressings to help prevent tissue damage.

Involve other members of the multidisciplinary team. Clinicians remain responsible to find ways of attaining comfort for the patient while implementing the most effective strategies to maintain skin integrity, however, when a patient/carer has capacity and continues to decline repositioning, this choice must be respected. Ensure that documentation reflects a complete record..

ND: When an individual or carer refuses to be repositioned time is required to be spent with them to identify the reasons why and find resolution. Full explanation of the need to reposition and the risks of skin damage should be discussed with the individual and/or carer and information provided for example pressure ulcer prevention leaflets. The aim should be to discuss and record an individualised prevention skin care plan with the individuals/carers goals clearly outlined within the plan and signed by both parties. The conversation should be clearly recorded within the individual's notes and discussion had with those professionals also providing care for the individual. Medication should also be reviewed if for example the individual is declines repositioning as pain may be an issue. Pressure relieving equipment should be advised following discussion with the individual/carer and implemented following agreement. However, every opportunity should be taken if the individual decides to be repositioned regardless of the time and frequency stipulated in their prevention care plan.

ETL: Developments in nurse education and training encourage nurses to be more proactive and to respect and value those in their care and their families. Hence, it's important for the health professional to recognise and respect when caring for an individual in the final stage of life that interchange is not exclusively verbal but also depends on observing facial expression, tone of voice and eye contact. The recognition of these emotions requires sensitivity when an individual refuses delivery of any form of intervention and preventative care and for some health professionals it may cause them to experience a feeling of professional failure and dereliction of duty, as they understand the rationale and the importance of preventing skin damage.

3. Is being close to the end of life a reason to stop pressure ulcer prevention?

LJ: I would not necessarily stop pressure ulcer prevention because a patient was dying, because as I have already discussed, the dying process could go on for various increments of time and can also fluctuate. However, if a patient is very unwell and perhaps in the last few days of life pressure ulcer prevention might need to be approached with more flexibility, for example less regimented turning schedules. In my experience patients, and their loved ones, are much more understanding and open to receiving care, if they understand why it is important and what the aim of the care is. It is important to monitor a patient's skin regularly where possible, in order to prevent causing unnecessary pain and infection from pressure damage. There are lots of options to be explored in addition to repositioning a patient, like barrier creams, different types of mattresses and protective dressings, but nothing should be used in isolation or without monitoring.

LC: In my opinion, definitely not. Sustaining a PU can result in distressing physical and psychosocial symptoms, and impact hugely on patients' quality of life and dying. If a patient sustains a painful PU, then this would also result in nurses having to spend more time dressing the wound, which can exacerbate symptoms, and intrude on quality time between the patient and family.

For some carers stopping PU prevention measures may be seen as giving up on their loved one and it is comforting for them to see that a high standard of care is continued until death.

The psychological effect on nurses should also be taken into consideration. Not providing measures that we feel are in the best interest of the patient can lead to feelings of guilt and failure.

The SCALE document offers valuable expert opinion, however, there remains much confusion regarding diagnosing skin failure, and its clinical acceptance, with alternative opinions out there, which appear equally valid. Until there is further clarification regarding SCALE, the debate will continue.

Personally, I would want to know that I had implemented every strategy to prevent my patients from sustaining a PU for the duration of care.

ND: End of life can last hours, days or weeks, so it would be difficult to say to stop PU prevention as soon as you believe the individual is at the end of life. We should aim to continue to prevent harm (pressure damage), even if it is just ensuring the individual is on the correct pressure relieving equipment and monitoring of the individuals skin is reduced in agreement with the individual and/or family. To stop PU prevention we could potentially cause harm to the individual, allowing pressure damage to occur, causing the individual to experience pain and discomfort. How can we then evidence good quality and safe care has been provided if we disregard the need for PU prevention at the end of life. Can we then say that this type of pressure damage is avoidable, following an investigation?

There is a need to address and discuss how the carer feels following a reported incident of pressure damage as guilt can be experienced by those caring for the individual, with often their need to justify their decisions and actions at that time. Therefore if PU prevention was to stop at the end of life, it needs to be the decision of the individual/carer, person caring for the individual and all those involved in the persons care and within guidance/policy. As there is a need to demonstrate and evidence quality care was provided and the individuals safety was maintained

ETL: I have been asked this on occasions and have personally being involved in the final stages of caring for a loved one. There are no definitive answers, but one should reflect on the understanding of all who participate in the care process and respect the individual and their carers consent, wishes and needs. Compassion, dignity and exemplary nursing care are vital in the final stages of palliative care and the health professional may experience a feeling of omission in failing their duty to deliver pressure prevention care if the patient refuses any form of care provision.

4. When would you consider stopping repositioning at the end of life??

LJ: If I thought a patient was in the last couple of hours of life then I might not attempt to reposition that patient anymore or at least delay repositioning of personal care unless absolutely necessary. This would likely need to be reviewed if the patient did not imminently die, particularly if any improvement was noted. This decision to delay care would need to be discussed with any loved ones present, as the perception might be that we were 'giving up' or perhaps being less attentive than usual. The main occasions I would delay repositioning would be if a patient was taking last breaths, or if a patient was waiting for loved ones to arrive to be with them. Sometimes repositioning a patient in this final stage can be too much for the patient and they might die before their visitors could get there. If a patient was in a position which looked to be causing them distress, I might suggest to loved ones that they stay in the room while we made them more comfortable, just in case the patient died in that short time period. Of course it is not always possible to delay care or for family or friends to be present, due to preserving the person's dignity or the nature of the care, for example in the case of severe incontinence or a terminal bleed.

LC: There would be very few instances when I would consider stopping repositioning, however, patient tolerance is key to this. If a patient is showing signs of distress or pain, then repositioning would not be appropriate, along with those patients who are at risk of a major event if repositioned/rolled.

When a patient has a preferred comfort position or when death is obviously imminent, repositioning would not be appropriate. If the patient or family are adamant that they do not wish repositioning to be continued, I would have to consider stopping repositioning.

If the decision is made to stop repositioning, then skin checks would still need to be performed to ensure that the patient's skin cleanliness is maintained, particularly when the patient is incontinent. The only exception to this in my opinion would be when the patient is in the last few minutes of life.

Personally, I believe that it is the nurses' responsibility to care for individuals to the end of life, which includes the provision of appropriate pressure-relieving equipment, and optimum care. All avenues would need to be explored before I would consider stopping repositioning a patient, even at end of life.

ND: Personally I feel we should try and continue repositioning, however, I have been involved in situations whereby prompts for considering stopping repositioning have been discussed, for example individuals experiencing extreme pain on movement, breathing difficulties etc. Only then this would be considered once every effort has been made for prevention and discussions with the individual/family and professionals involved in their care.

Stopping repositioning (or pressure prevention) can cause conflicting emotions, your aim is to do the best you can for the individual, ensuring their safety, dignity and comfort is maintained. However, by stopping repositioning and potentially causing pressure damage, personally you feel guilty, judging and analyzing every action and decision made and whether it was the right decision. As you are aware there is a need to report pressure damage, which can sometimes (i feel) be the focus to consider continuing repositioning. I feel consensus to consider stopping repositioning should be always aim to be the individual/family and individuals team.

ETL: Watching a loved one decline is almost intolerable and requires exceptional care and sensitivity from the multidisciplinary team towards the person and those around them. The situation and decision to stop repositioning should not be taken lightly but one should respect the wishes from the person/or family member and we must always assume the individual is aware of surrounding sounds, a human voices and the importance of touch. One could adopt the moral ground that we should maintain intervention to the end as to withhold pressure care of the dying may be interpreted as a failure of care. The dichotomy being a need to follow policy versus the need to respect the individuals wishes/that of their family, and to follow the instinct of the nurse/caregiver to know from the person's body language/facial expressions what is appropriate to do.

Nurses/caregivers need to be empowered to act in the best interest of those they are caring for, without fear of retribution for not following the policies/procedures set out. The rationale for that being the experience of someone in the final stages of life is lonely and impersonal but they still have an opinion and if conscious may well ask for rest and peace, to be left alone with their loved ones as this is the reality in some situations.

ACKNOWLEDGEMENT

Trudie Young would like to thank to Helen Way, Lead Nurse, Palliative Care, Velindre UNHS Trust for her guidance and contribution

REFERENCES

European Pressure Ulcer Advisory Panel, National Pressure Injury Advisory Panel and Pan Pacific Pressure Injury Alliance. Prevention and Treatment of Pressure Ulcers/Injuries: Clinical Practice Guideline. The International Guideline. Emily Haesler (ed). EPUAP/NPIAP/PPPIA: 2019

General Medical Council (2010) Treatment and care towards end of life: good practice in decision making. [Online] www.gmc-uk.org/guidance (accessed 2 November 2020)

National Health Service Improvement (2018) Pressure ulcers: revised definition and measurement. Publication code CG 73/18

Sibbald RG, Krasner DL, Lutz J (2010) SCALE: Skin Changes at Life's End: Final Consensus Statement: October 1, 2009. Adv Skin Wound Care 23(5): 225–36

World Helath Orgainisation (WHO) Palliative care. https://www.who.int/cancer/palliative/definition/en/ (accessed 2 November 2020)