Supporting Shared Decision-Making

to achieve concordance

Strategies for shared decision-making

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Strategies for shared decision-making

The power balance in healthcare has changed significantly in the last 50 years. Where previously, healthcare professionals held all the knowledge and power and patients were recipients of this, people now readily seek multiple 2nd opinions, either from other people or, by accessing medical publications and other less reliable sources of information via the myriad of search engines available. Following the commitment to 'Marthas rule' from NHS England's Health Secretary in September 2023, patients and families seeking such second opinions is likely to become much more common practice (Church, 2023).

This significant shift was demonstrated clearly during the COVID 19 Pandemic where the role of social media and social media influencers was leveraged to both encourage individuals to comply with government recommendations and also to discredit them.

The widespread adoption of smart technology, be that smart phones or watches and other devices that can monitor health, allow people to be more aware of their own bodies and health status. This coupled with easy access to the internet (Scull, 2020) means that patients frequently arrive to their consultations having completed comprehensive research which can (depending on their ability to search) result in them being very knowledgeable about their condition and what to expect or on the other hand can give them completely unrealistic expectations of what may happen to them (Pitt and Hendrickson, 2022).

Epstein et al., (2022) demonstrated the power that search engines have to alter thinking and behaviour by showing people biased search results. Many people are completely unaware that the ordering of results via any online search generally relates to the amount someone paid to have their information there – so information that appears first in the search list may have a commercial bias.

In addition to these changes in availability of information there are, of course significant changes in the way healthcare is delivered. In the 1960s and 1970s doctors and nurses were regarded as 'Gods' or 'Angels' presiding over patient care, with patients remaining in hospital to be tended to and cared for as passive recipients of care. This continued in the community when District Nurses had ample time to see each patient, to get to know them, understand them and their families and be involved not just in the patient health optimisation aspects but also the minutia of their daily life, resolving social issues, having time for cups of tea, helping with shopping – things that would be unheard of in the current healthcare context. All of these behaviours elevated the status of clinicians, they were well respected and revered – it was unheard of to challenge a doctor or nurse's advice.

When this change in knowledge and attitudes is combined with the changes in how health care is delivered, it is unsurprising that individuals now feel more empowered to voice what they will or will not do, or how they will do it.

These changes are reflected in the language used to describe the paternalistic clinician:patient relationship. Historically, patients were expected to be compliant with care, they were the passive recipients, expected to be obedient to the clinicians' recommendations and prescribed treatments. As it became increasingly accepted that patients could have a say in their care, 'adherence' was the language adopted within healthcare to connote a somewhat less paternalistic perspective emphasising "the extent to which the patient's action matches the agreed recommendations" (NICE, 2009a).

The terminology then moved towards the use of concordance, "the process of enlightened communication between the person and the healthcare professional leading to an agreed treatment and ongoing assessment of this as the optimal course" (Fawcett, 2020).

More recently organisations such as NHS England (2023a) have described a new way of working, with new terminology, built on shared decision-making; a relationship between people, professionals and the health and care system. It provides a positive shift in power and decision-making that enables people to feel informed, have a voice, to be heard and be connected to each other and their communities. They recognise that people want to have choice and control over the way their care is planned and delivered, based on 'what matters' to them and their individual strengths, needs and preferences. This is a very different way of working that significantly increases the likelihood that people will adopt behaviours and approaches that contribute to their health and wellbeing.

The objective of the document

To explore the concepts of person centredness and shared decision-making within the context of pressure ulcer prevention and management.

To describe some of the definitions used within this realm and to explore the impact of the language used during conversations with people, their families and carers.

To offer consideration as to the reasons why people may choose not to follow a Health Care Practitioners (HCP) advice or recommendations.

To provide recommendations for individual approaches and organisational culture changes that may seek to improve shared decision-making practices when agreement is difficult to achieve.

To provide some practical advice and solutions for HCPs when the person they are caring for is declining interventions the HCP believes are important to prevent/ treat pressure ulcers.

Note: this document may use the terms patient when referring to people engaging with healthcare and within examples or people/person when referring to people who may be within or outside of healthcare.

Background

There are multiple themes understood to influence the outcome of a person developing a pressure ulcer whilst receiving care. They all usually relate to the aSSKINg framework (National Wound Care Strategy Programme, 2023)– that is one or more of these elements of preventative care was not provided or documented as being provided. On occasion these actions were omitted because of person choice – they may have declined to have their skin inspected as part of their risk assessment, they may have declined to be repositioned or to have pressure reducing equipment. The approach, once risk has been identified, has traditionally been driven by the clinicians need to ensure the aSSKINg bundle aspects of care are delivered. Often this sits within an organisational policy or guideline advising staff what must happen when risk, or a pressure ulcer is identified. On occasion however, this focus on policy can result in the person's wishes and beliefs not being considered at the very beginning of the relationship.

During pressure ulcer investigations the clinical documentation regarding the person's refusal is too often inadequately written. It may be overly brief with no evidence of

- exploration of the person's wishes,
- an informative discussion to support decision-making or
- any exploration of the reasons why the person is declining the intervention.

The authors of this paper believe simply writing "patient refused mattress" or "patient declines skin checks" without further narrative is inadequate. Subsequently, should the person go on to develop a pressure ulcer, the investigation into determining the causes of this cannot ascertain that their refusal to adopt suggested preventative care was a contributory factor given that they may not have been fully informed of all the facts, alternatives, risks and benefits of
not adopting said intervention. This approach seems very health service driven and risk adverse and offers little in the way of acknowledging a person-centred approach, this document has been produced in order to support clinicians to:

- understand person centred healthcare in the context of pressure ulcers,
- empower shared decision-making with regard to PU prevention, treatment and management
- consider how to hold supportive conversations with people at risk
- document outcomes in a more balanced way.

Definitions and Language

The language that is used around building person-centred care, concordant relationships and shared decision-making may have an impact on the outcomes. In addition the language used can tell us something about culture. This will be discussed further later on.

Commonly today, the term non-concordant is used when clinically recording when people are declining aspects of care that clinicians believe to be best for them or necessary to treat or prevent harm. Other terms such as noncompliant and nonadherent have also been used.

Let's consider some of the words used when discussing care planning with people and their decisions regarding this.

Definitions /Glossary

Adherence: definition (www.dictionary.com): a noun meaning the act or state of adhering; adhesion

Adhere: definition (www.dictionary.com): a verb, to adhere meaning to hold closely or firmly to something (a plan of care for instance).

Compliance definition (www.dictionary.com): a noun meaning the act of conforming, acquiescing, or yielding; a tendency to yield readily to others, especially in a weak and subservient way; conformity; accordance -in compliance with orders; cooperation or obedience.

Concord Definition (www.dictionary.com) : a noun meaning agreement between persons, groups, nations, etc.; concurrence in attitudes, feelings, etc.; unanimity; accord. Accord means to be in agreement or harmony and discord is lack of concord or harmony between persons or things.

Concordance definition (www.dictionary.com) : a noun meaning agreement; concord; harmony. Snowden et al., (2013) described concordance as "the process of enlightened communication between the person and the healthcare professional leading to an agreed treatment and ongoing assessment of this as the optimal course".

Consent: Informed consent is an ongoing agreement by a person to receive treatment, undergo procedures or participate in research, after the risks, benefits and alternatives have been adequately explained to them (RCOT, 2021). *"For consent to be **valid**, it must be given voluntarily by an appropriately informed person who has the capacity to consent to the intervention in question (this will be the patient or someone with parental responsibility for a patient under the age of 18, someone authorised to do so under a Lasting Power of Attorney or someone who has the authority to make treatment decisions as a court appointed deputy). Acquiescence where the person does not know what the intervention entails is not 'consent'"* (DoH, 2009). *"It must be given voluntarily and freely, without pressure or undue influence being exerted on the person either to accept or refuse treatment"* (DoH, 2009).

Culture: definition (www.dictionary.com): a noun. Multiple definitions, for example; growing cultures such as in microbiology; the quality of a person or society with concern to the arts or scholarly pursuits; a particular stage of civilisation as that of a certain period or nation; development of the mind by education. With regards to the culture within an organisation or an individual however the following are better definitions:

- the total of the inherited ideas, beliefs, values, and knowledge, which constitute the shared bases of social action

- the total range of activities and ideas of a group of people with shared traditions, which are transmitted and reinforced by members of the group

Decline: definition (www.dictionary.com) : a verb, to withhold or deny consent to do, enter into or upon, etc.; refuse:
to express inability or reluctance to accept; refuse with courtesy: to decline an invitation; to decline an offer.
Authors note: as this word is defined as refusing with courtesy the authors have chosen to use this word throughout. It is worth noting though that the Nursing Midwifery Council, Royal College of Occupational Therapists and the Department of Health all use the word refuse.

Definitions /Glossary *continued*

Discord: definition (www.dictionary.com): a noun meaning lack of concord or harmony between persons or things: or disagreement; difference of opinion. A verb meaning to disagree; be at variance.

Noncompliance: definition (www.dictionary.com): a noun meaning failure or refusal to comply, as with a law, regulation, or term of a contract.

Nonconcordance – not found in www.dictionary.com. Suggests it is more correct to use discord when referring to a state of not achieving concordance.

Patient: definition (www.dictionary.com): a person who is under medical care or treatment.

Person: definition (www.dictionary.com): a human being, whether an adult or child. People is the collective descriptive word for persons.

Personalised care: represents a new relationship between people, professionals and the system. It happens when we make the most of the expertise, capacity and potential of people, families and communities (NHS England, 2023a).

Person-centred Care: *"healthcare that treats a patient as a whole person, with interests and commitments beyond narrow biomedical concerns"* (Mitchell, Cribb and Entwistle, 2023).

Person-centred Practice: *"an approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development"* (McCormack and McCance, 2016)

Refuse: definition (www.dictionary.com) : a verb. To decline to accept (something offered); to express a determination not to do something.

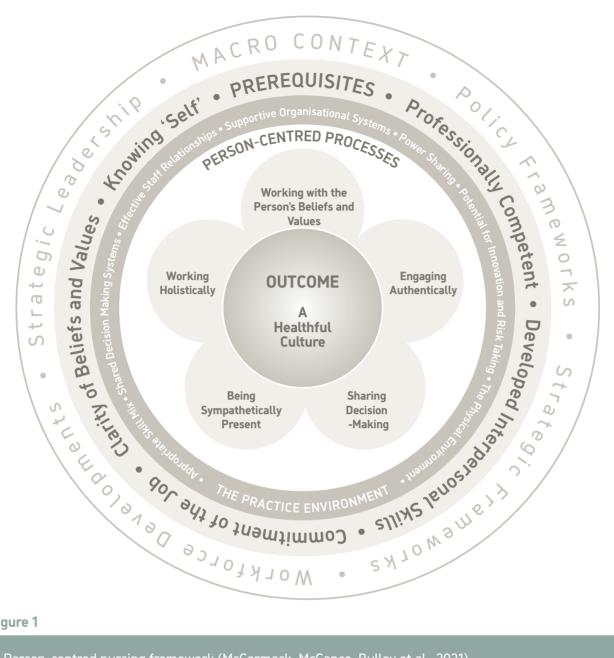**Reject: definition (www.dictionary.com):** a verb. To refuse to have, take, recognise.

Shared Decision-Making (SDM)- is a collaborative process that involves a person and their healthcare professional working together to reach a joint decision about care (NHS England and NHS Improvement 2019; NICE, 2021a).

Person-centred healthcare

Implementing person centred practice is a complex process requiring depth of understanding on many levels including:

- Considering what do person, and self, mean?
- What skills, beliefs, values, and commitments are needed by professionals?
- What organisational cultural change is needed to enable a person-centred healthcare system?
- What needs to be considered in how care is delivered?
- How is person centred healthcare embraced by a care provider, and does its values support person centred practice?

Putting an end to clinical records that state "patient refused" and moving towards an organisational framework that supports person centred healthcare may require paradigm shifts at multiple levels. McCormack and McCance (2016) have designed and tested (McCance et al., 2021) a practice framework that can support implementation of person-centred practice (Figure 1).

Figure 1

Person-centred nursing framework (McCormack, McCance, Bulley et al., 2021)
[permission https://www.pcp-icop.org/membership-benefits]

The 4 domains of this framework begin with prerequisites that need to be considered and made live in order to move through to considering the practice environment, and then the person-centred processes that must be embedded in business as usual practice in order to achieve the person centred outcomes sitting centrally.

The 5th domain, called the Macro Context, reflects factors that influence person-centred culture development.

Culture

Culture can influence the attitudes, behaviours and beliefs of HCPs (Mannion and Davies, 2018). The culture can be organisational, departmental, team or individually based. A Healthcare organisation is likely to comprise of multiple subcultures (Mannion and Davies, 2018).

The Care Quality Commission (CQC for England) (2023a) and the Care Inspectorate (for Scotland) (2018) follow 5 key questions and quality statements when inspecting a care provider organisation. One of which is whether the organisation, department, team is Well-led. Examples of statements to demonstrate this are:

- *"There is an inclusive and positive culture of continuous learning and improvement"*

- *"We have a shared vision, strategy and culture"*

- *"We have inclusive leaders at all levels who understand the context in which we deliver care, treatment and support and embody the culture and values of their workforce and organisation"*

- *"Strategic leaders strove to create a strong, person-centred, improvement focused culture and ethos for adult support and protection. It was underpinned by a principle of transparency and a learning culture."* (Care Inspectorate, 2023)

Example Box 1

As an example of how the CQC measure culture (2022) within an inspection the report for Birmingham Women's and Children's NHS Foundation Trust (CQC, 2023b) mentions culture in relation to the following : open and transparent; being heard; respect, support, being valued, being able to raise concerns without fear; honesty; centred on needs and experience of service user; incident reporting culture; research culture; When staff assessed patients as not having capacity, they made decisions in the best interest of patients and considered the patient's wishes, feelings, culture and history; equality & diversity; respectful; no blame culture; Patient's nutrition and hydration needs (including those related to culture and religion); positive culture; open culture; a culture where staff are proud of the work that they and their colleagues do; inclusive culture.

Things to do or think about. Culture

It is important to consider this within your own organisation, department, team. If you feel the above describes your organisation and service, you are more likely to succeed in implementing SDM (if you haven't already!).

However, if the culture in your organisation is not conducive to a positive culture or SDM making then staff may feel unsupported to embed it. See Box 2

NICE (2021a) recognise that embedding SDM in an organisation is linked to culture and leadership. When senior managers and leaders are committed to SDM, they will make resources to instil it available and support a culture of involving people who use services across the whole organisation.

Example Box 2

Culture is described very differently in the Stafford Inquiry (Francis, 2013). Examples within the Inquiry describing the concerns are: *" failed to tackle an* **insidious negative culture** *involving a tolerance of poor standards and a disengagement from managerial and leadership responsibilities; A culture focused on doing the* **system's business – not that of the patients**; *An* **institutional culture** *which ascribed more weight to positive information about the service than to information capable of implying cause for concern; A failure to tackle challenges to the building up of a positive culture".* Recommendations regarding culture were: *"Foster a common culture shared by all in the service of* **putting the patient first**; *move successfully away from the* **culture of blame**; **Patients must be the first priority** *in all of what the NHS does; There should be an increased focus on a* **culture of compassion and caring***"*.

Of particular consideration is an organisation's culture is the following statement *"The understandable human need to identify one or more people to be held to account means that whenever something goes wrong a hunt starts, and the larger the disaster the more pressure there is. Thus a factor in the pressure leading to this Inquiry was a wish to see people brought to account, whereas if an inquiry is to fulfil its main purpose it has to identify lessons to be applied."* (Francis, 2013).

This can be true in the field of pressure ulceration. Investigations into why a PU developed may centre on blame rather than learning. Organisations, teams, or individuals may point the finger at each other raising unhelpful safeguarding concerns without any understanding of the true root causes behind the PU development. When a HCP is offering a patient a mattress (as an example) to prevent pressure ulcers and they decline the offer and the HCP then records *"patient refused mattress"* without any further exploration as to why this is, they are essentially behaving within a blame culture. On this occasion the blame is being laid firmly at the feet of the patient. Where a learning culture exists, the focus will be on understanding what did not go to plan and why, or on what went well, not on apportioning blame.

A person may have many different cultural influences, beliefs or experiences contributing to their decisions. A HCP within an organisation who adopts person centred care will seek to understand what these may be. By asking about and listening to their beliefs/thoughts/feelings/reasons and being clinically curious (seeking to understand why), an understanding of supporting a person centred care plan can begin.

Understanding an organisation's culture

If a healthcare organisation is interested in understanding it's culture it may decide to undertake an assessment (Mannion and Davies, 2018; The Kings Fund, 2023). If an organisation has undertaken such an assessment, it may be found on the organisation's intranet. An example of such a cultural assessment can be found here https://www.kingsfund.org.uk/publications/articles/understanding-organisational-culture .

Mannion and Davies (2018) describe 3 levels of organisational culture in healthcare:

- Visible manifestations (how services, roles, buildings, pathways, etc are distributed or laid out and how risk or quality improvement are managed)

- Shared Ways of thinking (the values and beliefs used to justify the visible manifestations) and

- Deeper shared assumptions (largely unconscious and unexamined underpinnings of everyday practice such as professional hierarchy or HCP Power).

All NHS trusts providing acute, community, specialist, ambulance, and mental health services in England are now required to participate in the National Quarterly Pulse Survey (NHS England, 2022a). This is an opportunity for Trusts to review staff experience and feedback and could be used to identify positive or negative cultural behaviours within the organisation.

> ## Things to do or think about
>
> If you believe culture within the organisation is poor, first approach your line manager about your concerns. If you feel your concerns are not adequately acted upon, then approach the Freedom to Speak Up Guardian or Ambassadors in your organisation. Every organisation in NHS England is required to have one of these (NHS England, 2022b). NHS England describes speaking up as *"a gift because it helps identify opportunities for improvement"*.

Shared decision-making (Person-centred Processes) What does it mean to be a person?

> ## Things to do or think about
>
> To understand this in the context of the people you care for first consider what this means for you.
>
> What makes you, you? What matters to you? What life experiences have shaped who you are and how you react to situations? What core beliefs and values do you hold?

There are a multitude of influences that will impact on how a person makes decisions about their healthcare. How they have lived their life. What their core values and beliefs are. What is deemed acceptable and unacceptable to them. What they want to happen. Their biases may be completely at odds with HCPs biases. These are just a few examples for HCPs to consider and be aware of when having discussions about care interventions. HCPs must also remember that a decision is made in a point in time in a given situation. This decision may change as time moves on and the person's situation changes, and keeping the lines of communication open is vital. HCPs can suggest to the person that they would like to revisit the conversation about PU prevention so they know this will happen.

SDM is a *joint process in which a HCP works together with a person to reach a decision about their care* (NICE, 2023). Making personalised care across the health and care system, business as usual is part of the Long Term plan (NHS, 2019)

and SDM forms a part of this. This ensures people are involved in discussions about treatments, investigations and care plans. It allows their individual preferences, beliefs and values to be taken into consideration and empowers them to make decisions that are right for them at the time they are making them. It also encourages people to choose to what extent they want to be involved in decisions – some people may prefer the HCP to make decisions for them whilst others may want to be involved in every decision at every stage.

An organisational culture and framework to support SDM will be necessary to ensure good practice becomes embedded.

This might involve

- training so staff can develop the necessary understanding and skills to have good SDM conversations

- documentation templates to support recording of SDM conversations and decisions made

- information tools (leaflets, passports) to support the patient in having all the facts to support their decision

- the introduction of patients' decision aid tools for use when necessary.

This will help staff feel supported to have confident conversations with people and will give them a feeling of safety when a person's final decision about their care is believed by the professional to not be a wise decision. If

harm later occurs, for example a pressure ulcer develops, and there is a good record of the SDM process followed in the person's clinical records then the HCP can feel assured that there are no omissions on their part that may have contributed to that skin harm.

Very often pressure ulcer prevention is about educating people about risk. How much do they understand their risk of developing a pressure ulcer? Do they understand the risk assessment and how the HCP has determined their risk status? Talking through the assessment with them and highlighting the individual risk factors associated with them can help them develop a broader understanding of actions that can reduce this risk (NICE, 2021b). See box 3.

There is little evidence to support the usefulness of information leaflets or other educational programmes for patients (O'Connor et al., 2021; Ledger et al., 2023). Consideration needs to be given to the person's ability to read, understand or to have the energy to read a leaflet or other written information (Ledger et al., 2023). People value the opportunity to talk the issue through when provided with this opportunity but if they feel the HCP is rushed or too busy they may not raise any concerns or queries with them (Ledger et al., 2023). Listening to them, involving them in the decision-making process and addressing or considering their concerns can help improve adherence to recommended prevention activities (Ledger et al., 2023).

Example Box 3

Telling a person they are at risk of getting a pressure because they have scored orange in PURPOSE T or 15 in a Waterlow score does not help them understand their risk. Showing them the tool and highlighting that they have scored orange because of peripheral neuropathy and have additional risk factors of poor nutrition and diabetes can support a conversation about what they can do to mitigate this risk. For instance – ensuring their feet are protected from pressure when sitting/resting/in bed; offering advice on how they can improve their appetite and nutritional intake and offering support to improve diabetes control can all help to reduce their risk. If we just say "you are at risk of getting a pressure ulcer and we suggest you need an alternating mattress because of this" we are not giving them all the facts behind their risk. We may also not be offering them a solution that will help reduce their risk as a mattress may not be the optimal solution for foot risk.

The probability of risk also needs to be discussed openly with the person at risk. How significant is their risk? What is their probability of developing a pressure ulcer? Can you tell them

what percentage of people in your care develop a pressure ulcer? If not, can you tell them what the figure is nationally? In the case of Montgomery vs Lanarkshire Health Board

(2015) the risk of birthing difficulties were withheld because *"it creates anxiety and mothers then want a caesarean section"*. This is an example of the HCP making decisions for the person at risk because of their own beliefs.

It may also be important to ensure that the person understands the severity and or extent of damage a pressure ulcer entails, without overly emphasising the negative aspects, as many may think it is only 'a sore bottom'.

Only mentioning the risk in negative ways *"if you don't have a mattress you will get a pressure ulcer"* or positive *"these air mattresses will stop you getting a pressure ulcer"* may be insufficient to help the person make an informed decision

(NICE, 2021b). In addition, neither of these statements are accurate or true. By framing it for them in numbers to treat, that is how many people had a mattress and how many benefited or the percentage of people you know develop PU in your establishment may be more informed information (SEE BOX 4).

Nixon et al (2019) suggested a need for improvement in targeting alternating pressure mattress with decision-making informed by patient preference/comfort/ rehabilitation needs as well as risk factors such as being completely immobile, nutritionally deficient, lacking capacity and presence of altered skin/category 1.

Example Box 4

Suggested facts and figures to share with people when discussing relative benefits of mattresses.

- *We know that in 2020 9% of patients in 18 hospitals had a pressure ulcer. Of these 19% were on the foot (ankle, heel, toe). (NHS England & Improvement, 2020).*

- *We know in our caseloads that less than 5% of patients have a pressure ulcer.*

- *In a clinical trial comparing alternating mattresses to high specification foam mattresses in 2019 people in hospital, 7.9% developed a pressure ulcer. 6.9% of those on an alternating mattress and 8.9% of those on a foam mattress (Nixon et al., 2019). It took on average 6 days longer for those on an alternating mattress to develop a PU (not statistically different). However, within the first 60 days of treatment there was a statistically significant difference between time to develop a PU with it taking longer on alternating mattresses. Of those with an existing PU, healing rates were similar in both mattress groups.*

- *This trial also determined that for every 50 patients allocated an alternating air mattress, one patient benefited.*

- *We have no evidence that tells us by how much using one of these mattresses reduces your risk but for those people who may develop an ulcer using an alternating mattress can delay onset by several days compared to using a foam mattress.*

NICE (2021b) go further to explain that just using the word risk could be deemed negatively by some people so when possible use risks, benefits and consequences to frame the discussion. Considering the example in Box 3, the real risk lies in their feet not feeling the sensation of pressure (neuropathy) and the consequence of not off loading or moving their feet could be skin damage. However, if they are mobile then this risk is reduced already. If they are not mobile then the

benefit of wearing an off loading boot in bed is that pressure is taken away so they don't have to worry about (a benefit) not feeling the pressure. For example: *"The consequence of not offloading the foot from pressure could be that a pressure ulcer will develop on the (heel/ankle/toe) and about 19% of people in our care who have a PU have one here, adding that 5% of people on caseloads have a pressure ulcer."*

Also, consider if the risk is temporary or long term. For example someone having hip surgery may have an increased risk post operatively but this may reduce quite quickly once they have recovered. The national audit (NHS England and Improvement, 2020) found that 8% of people with a therapeutic mattress (alternating or hybrid) did not need one according to their risk profile. Equally, 10% of people who would be deemed to require one according to their risk profile did not have one. Arguably, when concordance is considered, it is the refusal of a mattress that features most often in root cause analysis.

Things to do or think about

When having the conversation with the person at risk regarding an alternating mattress have you:

- Ascertained the need to talk to them about this

- Identified their risk level and shown them how this was reached

- Ascertained that a mattress is the solution to their risk problem and not another solution such as repositioning or foot offloading

- Provided them with information about pressure ulcers [see box 5] and discussed with them and provided opportunities for questions

- Explained the probability of them actually going on to develop a pressure ulcer without the intervention [see box 4]

- Considered how long you think they need to have the mattress for to most benefit from it

- Considered what one of these mattresses is and how it works and will feel for them

- Considered the risk of the mattress negatively impacting on their ability to independently move in bed and in and out of bed

- Considered what other equipment might be needed in order to use the mattress, such as a profiling bed

Example Box 5 Resources that can be shared with people

1. *The 5 key messages to prevent pressure ulcers video resource*
   https://www.youtube.com/watch?v=Syc-hByVGF0

2. *National Wound Care Strategy Programme (2023)*
   https://www.nationalwoundcarestrategy.net/pressure-ulcer/

3. *NHS https://www.nhs.uk/conditions/pressure-sores/*

4. *NICE PU information for the public*
   https://www.nice.org.uk/guidance/cg179/ifp/chapter/About-this-information

5. *Spinal Injuries Association*
   https://www.spinal.co.uk/wp-content/uploads/2022/06/SIA_Pressure_Ulcers_Factsheet_v2.pdf

If, having received the facts, risks, benefits and consequences of a mattress they decide to decline using one, consider what alternatives can you offer them [for example: repositioning more often, a topper mattress in foam or air, other positional/posture aids].

Have the consequences of developing a pressure ulcer been discussed with them and do they have a clear understanding of these? In order to be fully informed they need to both understand their risks and also the consequences.

Things to do or think about. Consequences of developing a PU

- Infection – wound and bone
- Sepsis
- Longer hospital stay
- Pain from the wound
- Inconvenience of requiring dressing changes
- Death
- Scarring

If however, after such a conversation the person still declines an intervention then persuasion is not a good tactic to use because they could be persuaded to make a decision that is not consistent with their beliefs or values (NICE, 2021b).

Using tools that can visually enable the person to understand how pressure is affecting their skin may support a better understanding of their risk. Pressure mapping has been used to help patients understand the extent of pressure and what they need to do to support PU prevention in themselves (Cornwall Partnership NHS Foundation Trust, 2022).

Language

Good use of language; verbal, written, and non-verbal which is more inclusive and values based, can lower anxiety, build confidence, educate and help to improve self-care (NHS England, 2018). Poor communication can be stigmatising, hurtful, undermine self-care and have detrimental effects on clinical outcomes (NHS England, 2023b).

The language and words used when talking with people about care interventions can reflect HCP bias towards a paternalistic relationship as well as support a person in coming to a decision in an informed way. In addition, how a HCP describes the interaction and outcome in the patients' clinical records can reveal their own beliefs and the culture within which they work.

Let's consider the language used by national documents/guidelines and codes when discussing a patient's right to make decisions that differ from the suggestions of the HCP.

Consistently the word refuse is used by all of the documents.

Professional codes consistently guide registrants to consider a patient's rights and choices when making decisions about their care. Registered professionals have a duty to enable, encourage and empower choice and SDM (Health and Care Professions Council, 2016; Nursing and Midwifery Council 2018; Royal College of Occupational Therapists, 2021). They are reminded that patients have the right to refuse a particular course of action, the right not to consent and to withdraw previously given consent, to decisions and actions affecting them (Chartered Society of Physiotherapy 2019; DoH 2009; NMC 2018; RCOT 2021). And, also reminded that they must respect their decision (NMC, 2018) even when it conflicts with their own (RCOT, 2021). However, they also need to balance acting in a patient's best interests and providing information, and continuing to do so, with respect of their

decisions even when this means them refusing to accept a care intervention (NMC, 2018; RCOT, 2021).

Both NICE (2021a) and the OT code (RCOT, 2021) go one step further and advise that healthcare professionals are not obliged to deliver care interventions that in their clinical opinion are deemed futile. A second opinion may be needed in these situations.

When conversing with patients to explain recommended treatment or prevention interventions, the language and wording used by the clinician can support a patient in their decision-making, either in a positive or negative way. For example, advising the patient that they have an ischial tuberosity pressure ulcer as a consequence of seating and posture, and that the best (and only) course of treatment for this is to remain in bed for 6 months is not going to sound like a positive treatment choice for the patient. Suggesting other treatment options and offering some compromise around bed rest may help them to accept that some bed rest is acceptable to them. If they can understand that total offloading is the optimum and minimal offloading is sub optimal then an agreement somewhere in the middle may be easier to meet.

In addition, and primarily, the language used may not be understandable to the patient. They may not understand the term pressure ulcer or the language used around risk but may be aware of bed sore (Ledger et al., 2023). In the example highlighted above, the use of ischial tuberosity will not be helpful – may be more useful to use sitting bone.

What is Concordance

Concordance is an agreement between two persons or parties. It is achieved through mutual agreement and in some instances negotiation. The Conference of the Parties (COP) under the United Nations Framework Convention on Climate Change (UNFCCC) have successfully agreed a climate pact that has almost every country, out of the participating 200, committing to the pact on some level (United Nations Climate Change, 2021).

Concordance is frequently used interchangeably with compliance and adherence (Fawcett, 2020), yet there are clear differences in the definitions, and intentions, of these terms. However, although concordance is intended to emphasise agreement between the patient and HCP there is often doubt regarding how involved the patient has been in the decision-making process (Fawcett, 2020).

Concordance can still be achieved around PU prevention, treatment and management even if the initial intervention suggested by the HCP was declined and an alternative has been agreed to. It is therefore not correct to describe a person as non-concordant. This term/phrase does not exist. This is discord – an agreement was not reached.

Human beings have the right to make decisions, even when these decisions appear to another, to be unwise. People take health risks all the time often knowingly and sometimes unknowingly. When cigarettes were first produced for mass use the detrimental health effects were largely unknown and advertisements promoting products often used health benefits to increase sales (Little, 2023). However, over time these ill effects became so well known that health warnings were added to packets and internationally there are huge health promotion programmes driving to reduce the number of smokers. And yet, still some people choose to smoke – some in conjunction with severe health conditions caused directly by the smoking.

Some people take risks for pleasure in sport and leisure. Many people will ignore health and safety precautions when undertaking household or work tasks, that lead to injury. In other words, making what some people might deem as unwise decisions is normal human behaviour.

It should, therefore, be no surprise that people receiving healthcare do not always wish to participate in care interventions and treatment that HCPs believe are best for them. The role of the HCP is not to condemn people for their perceived poor decisions but, to find a way to understand their decision, reach a middle ground where possible and be confident the risks and benefits of the suggested intervention/treatment and their decision are fully understood. This does not make them non-concordant. On the contrary a concordant agreement has been reached with understanding and agreement.

Ledger et al., (2020) identified three themes that might influence a person's adherence to care interventions

- individual/daily lifestyle considerations,
- patient involvement in the decision-making process, and
- pain and/or discomfort.

And in 2023 Ledger et al., found many factors influenced the patient's likelihood to adhere to advice regarding PU prevention including

- pain
- fear of falling
- visual problems
- fatigue and
- long-term conditions (competing priorities).

There can be many influencing factors that can impact on the development of concordance around healthcare

Having person centred discussions
Considering the language used when engaging in discussions with people about recommended modes of prevention or treatment, can also enhance the likelihood of success or failure to reach concordance.

If a HCP believes they "know best" it is likely to influence their use of language when discussing care interventions with people. It could be directive, coercive or be perceived as threatening. If a HCP is approaching a conversation with a patient from a viewpoint of reaching a shared decision then language might be more exploratory and informative.

In PU prevention and management the care interventions patients most frequently decline might be

- an alternative mattress to their own
- an electric profiling bed
- an alternating mattress

- repositioning at a time schedule they deem too often or to a position they find unacceptable
- skin assessments
- changes to their nutritional intake.

Examples

Threatening:
"We want you to have this mattress to stop you getting a bed sore – if you don't have this mattress, you will get a bed sore (we call them pressure ulcers) and might get a nasty infection and die"

Exploratory and informative:
"We have talked about bed sores before and about what they are and how harmful they can be – can you recall what we said when we talked about them before? I am noticing that your skin is changing colour despite you moving more often. As such we may need to think about your posture, you moving more frequently or we could add in a different type of mattress/cushion to reduce the pressures over your bone. How would you feel about that?"

Patient Decision-Making Aids

Patient decision aids are tools designed to help people participate in decision-making by providing information about options, associated benefits/harms and helping clarify agreement between decisions and personal values (Stacey et al., 2017). They provide information on the options and help people clarify and communicate the personal values they associate with different features of the options. Stacey et al., (2017) found people were more knowledgeable, better informed, had better risk perceptions, were clearer about their values, and probably have a more active role in decision-making. However, they concluded further research is needed on the effects on adherence with the chosen option.

Patient decision aids (PDA) are not meant to replace HCP conversations or advise people to choose one option over another (Volk et al., 2013). Instead, they prepare patients to make informed, value-based decisions with their HCP. The development of PDAs is a complex process, one that must be rigorous and tested (Elwyn et al, 2006; NICE 2021a, 2023).

Things to do or think about

- Investigate whether there are any patient decision-making aids in use in your organisation already. Is there one to support PU prevention conversations?

- If not, is this something you can develop?

Useful links for development of PDA tools
(see reference list for full details where applicable)

Elwyn et al. (2006) Developing a quality criteria framework for patient decision aids

IPDAS International Patient Decision Aid Standards http://ipdas.ohri.ca/index.html

NHS England Decision Support Tools
https://www.england.nhs.uk/personalisedcare/shared-decision-making/decision-support-tools/

NHS England How to make shared decision-making happen https://www.england.nhs.uk/personalisedcare/shared-decision-making/how-to-make-shared-decision-making-happen/

NICE (2021c) Standards framework for shared-decision-making support tools, including patient decision aids

NICE (2023) NICE decision aid process guide

Motivational interviewing

Motivational interviewing is rooted in the field of counselling and aims to strengthen personal motivation, elicit a person's reasons for change and to set their own goals to bring about a change in behaviour (Copeland et al, 2015).

As HCPs, with the best of intentions, there is often a tendency to encourage, persuade and to convince someone to change their behaviours by giving them all the reasons why it is important. This approach can be viewed as authoritarian and create barriers to change (Miller and Rollnick 2012; Montgomery (Appellant) v Lanarkshire Health Board 2015). Miller and Rollnick (2012) promote a guiding approach, coming alongside the person to help them to work out solutions for change for themselves, exploring the why and the how they may change.

Communication

There are numerous communication tools to aid in framing your discussions. **SPIKES** developed by Baile et al (2000) was originally developed for breaking bad news. However, the six steps are aimed at gathering information, giving information and working in partnership with the patient to develop a strategy for their care, thus promoting patient-centredness.

S — **Setting up the interview** – Somewhere private, involving significant others where appropriate, sit down, make a connection (this may be eye contact or touch), manage time constraints and interruptions.

P — **Assessing the patient's Perception** – what does the patient already know? This will frame what comes next and supports the HCP in gathering information and knowledge about their patient before they start giving it.

I — **Obtaining the patient's Invitation** – What do they want to know, what do they not want to know. Not every patient wants to know everything about their condition.

K — **Giving Knowledge and information to the patient** – Use non-technical words, small amounts of information at a time, ascertaining how they like to receive information.

E — **Addressing the patient's Emotions** - Allow time for the patient to express their emotions. Observe for any emotion, try and identify what the emotion is and the reason for the emotion, Acknowledge the emotions, it shows you are listening. Offering empathetic statements can support this for example; *"I can see that you are very upset/sad/angry /confused. You have a lot to deal with, or I can't imagine how you must be feeling, would you like to tell me?"*

S — **Strategy and Summary** – What does the patient want, what options can you offer. What plan can you come to together? Summarise the plan to make sure all have understood and agree.

Egan (1975) developed a framework that guides making a positive connection before and during the conversation focusing on non-verbal communication. More recently Stickley (2011) adapted this framework to make **SURETY**.

S	Sit at an angle to the client.
U	Uncross legs and arms.
R	Relax.
E	Eye contact.
T	Appropriate use of Touch, sensitivity is important. Touch can convey compassion but considerations around personal space should be assessed.
Y	Trust Your own intuition in the situation. There are no guidelines for using intuition but experience and knowledge of the patient can be used to guide a discussion.

Motivational Interviewing - Traps to avoid

Rollnick (2022) identifies five potential traps when undertaking motivational interviewing. Being aware of these may help to avoid them.

1. The expert information dump trap – As HCPs with knowledge and experience it is only natural that we want to inform and educate. Fogelberg et al., (2016) found that education can increase knowledge but does not always illicit behaviour change. Too much information can be overwhelming causing a person to disengage.

2. The persuasion trap – persuasion involves giving reasons why a person should change. However, if the person has not yet come to the point of why they should change for themselves they are likely to find all the reasons why they shouldn't.

3. The deficit detection trap – this involves the HCP believing they know what is best for the person, finding their deficits and trying to rectify them.

4. The labelling and blaming trap – the approach should be one of curiosity, acceptance and compassion.

5. The premature focus trap – The HCP believes they know the answers and tries to employ practical solutions before the person has come to their own why and how for themselves.

Motivational interviewing should not be considered as a one-off event. The conversation may need to be revisited, but care should be taken as some patients may feel bullied. However, previous issues may need a better understanding, new issues may arise that require discussion and new strategies may need to be agreed.

Difficult Situations

NHS England (undated) have developed a training programme for handling difficult situations with compassion, including using appropriate communication techniques and active listening skills, whilst focusing on how to keep yourself safe and seek support if you feel affected by a situation. The pilot undertaken in 2021/22 reported a 25% increase in confidence in handling difficult situations with compassion following the training. The training is delivered with virtual sessions or via e-learning for Healthcare (2023). **https://www.england.nhs.uk/supporting-our-nhs-people/support-now/handling-difficult-situations-with-compassion-training-programme/**

Things to do or think about

Consider attending the handling difficult situations with compassion training

Tips for managing difficult situations:

- Recognise that it is human to have feelings and emotions
- Do not lose your temper, raise your voice, get angry, sarcastic or provocative or attempt to humiliate the aggressor
- Take a deep breath, relax, and remain calm, neutral and respectful
- Do not react and start disagreeing; pause and think before acting
- Say 'No' to unreasonable demands, but be prepared to manage any adverse reaction
- Do not tell the person that you know how they feel but do try to see the situation from their perspective
- Show warmth and empathy
- Do not let a bad experience with one person affect your whole day/shift or your family life – keep a sense of perspective and a professional attitude

(Ali, 2018)

Professional or clinical curiosity

Curiosity is defined as "an eager desire to learn or know about anything". "It's simply the drive for learning more about your patients, their conditions and life" (Petika, 2022). Demonstrating clinical or professional curiosity is therefore when a HCP

- becomes inquisitive about what is causing someone to be unwell (reaching diagnosis),
- wishes to understand about the person they are caring for including their beliefs and wishes,
- wishes to understand the motivations behind that person's decisions around health and social care
- wishes to understand what might be behind certain behaviours such as anger masking anxiety
- asks why.

It is simply not taking at face value what the person is communicating and seeking to dig a little deeper to understand their goals, values and beliefs. Discussions that come from a person-centred foundation – ensuring the person feels their opinions values and beliefs are part of any SDM process – can support the achievement of concordance.

There has been a shift in the climate in healthcare, possibly due to the staffing crisis and increased dependency of patients with increased healthcare needs, from having time to spend with patients to care becoming task orientated (Sharp et al., 2018). In the community setting, this has moved HCPs further and further away from person centred care (Maybin et al., 2016). This climate means HCPs are fatigued, frustrated, unsatisfied, and busy. So, when a HCP is advising a patient to have or do something that the HCP believes

will serve them well and the patient is refusing, the HCP can become frustrated which is exacerbated by the current climate described above. HCPs can feel they don't have time to discuss this further to offer explanation meaning no discussion takes place. In some areas the patient is then blamed for their poor decision and 'patient refused' is written in the clinical records.

However, taking some time to be clinically curious and explore why the intervention has been declined can save time and harm if a PU is prevented.

Example of clinical curiosity in practice:

Patient – *"I'm not using that mattress (alternating replacement mattress)"*

HCP – *"Can you help me understand the reasons behind this decision?" [Clinical curiosity - consider this wording versus "why not?" Which is confrontational Or "if you don't then you will get a PU", which is threatening].*

Patient – *"it's too noisy/makes me sweat/makes me feel seasick/it's uncomfortable/I can't sleep on it"*

HCP – *"OK. I understand that. What do you understand about pressure ulcers (also known as bed sores) and what the benefits of this kind of mattress are?" [clinical curiosity]*

Patient – *"They happen to really old people and these mattresses are to stop them getting a bed sore"*

HCP – *"PU can occur in anyone of any age. They happen because of reduced mobility – [explain how PU develop.] We have assessed your risk of developing a PU and because you are in bed most of the time and cannot move out of bed without assistance this increases your risk of getting a PU. There are several things we can do to reduce this risk. The mattress won't necessarily stop you from getting a PU – we know from research that people can still develop PU on these mattresses, almost as often as those on pressure reducing foam mattresses like you have already in fact, although it may take a bit longer to develop on the air mattress. 50 people need to be cared for on an air mattress for one person to be prevented from getting a PU. The most effective way to prevent them is to move and change position. Let's consider how you can move more in bed. What can you do to move yourself and let's look at how we can use the profiling bed to change your position. Another alternative is to use a topper air mattress that goes on top of your current mattress but isn't plugged in and adds an additional layer of pressure reduction. The keeping moving is still important though".*

Patient – *"OK, can I try the topper first and can we talk about how I can move myself more?"*

HCP – *"Of course, and if that doesn't seem to be helping reduce the risk – we will know this by noticing changes in your skin such as change in colour, pain, numbness over the pressure areas – perhaps we can revisit this discussion about the alternating mattress and see if there are other options to help you feel able to give it a try"*

Other considerations around a curious conversation for this scenario could be: exploring if nausea is linked to the mattress or a separate unmet care need which may need investigating.

Other solutions could be to discuss the settings on the mattress – can it be switched to constant low pressure from alternating for instance.

Allow room to revisit the decision in a mutually agreed timeframe, for instance in 2 nights time.

Document the outcome and mitigations – i.e. remove mattress but negotiate more frequent repositioning/skin inspections.

Note the above example requires time, skills in person centred care and clinical curiosity.

Scenarios

This section may be useful to give some context in different scenarios.

Expert patient

An expert patient is a term used to describe a patient who has developed a deep understanding of their own medical condition and healthcare needs and is actively involved in managing their own care (Goovaerts et al., 2015). Expert patients are knowledgeable about their condition and may have developed expertise in areas such as symptom management, medication management, and navigating the healthcare system.

The concept of the expert patient (DoH, 2001) has gained recognition in healthcare over the past few decades, as healthcare providers have come to recognize the importance of patient empowerment and patient-centred care. By taking an active role in their own care, expert patients can improve their quality of life and health outcomes, while also reducing healthcare costs and improving the efficiency of the healthcare system.

Badcott (2005) reviewed some of the major issues surrounding the expert patient and concluded that encouraging patients who have experience of their condition in decisions, could have benefits for both patients and health professionals if operated on the basis of concordance: an informed collaborative alliance that optimises the potential benefits of medical care.

Expert Patient

A 43-year-old lady with spina bifida is occasionally admitted to hospital with acute urinary infections requiring hospital management. On one such occasion when she was younger she was given an alternating pressure mattress because of her risk assessment score. Usually independently mobile, being able to get herself in and out of bed, from and to her wheelchair, the mattress had the negative consequence of immobilising her, making it difficult to move in or out of bed. She subsequently developed a pressure ulcer that took many months to heal. As such, whenever she is admitted she always refuses the alternating air mattress. Staff, however often try to cajole her into having one which causes her much distress because she does not feel heard and she feels they don't believe her.

End of Life

Person centred holistic end of life care requires finding out what matters to each individual so that an agreed, personalised care plan can be established.

Concordance in end-of-life care is about knowing the person you are caring for.

Consider: "What matters to them? What are their goals? Would they want treatment at all costs, or do they prefer to focus on quality of life? Putting life into days rather than days into life. If they become so ill that they could die, what does this look like to them? Have they thought about their end of life? Have they shared their wishes with family and friends? Do they need a Lasting Power of Attorney to speak for them when/if they become too unwell to speak for themselves? What worries or concerns do they have?"

Palliative care is a multidisciplinary approach, many heads together are better than one when making difficult decisions. Patients often have complex needs and holistic care delivery requires teamwork and good leadership. Risk taking isn't always embedded into clinical practice but for end of life to be maximised based around personalised care, this often involves risk.

Most relationships, in whatever form, require compromise and caring for someone at the end of their life is no different.

Phrases like "pulling all the stops out" or "going the extra mile" to transfer a deteriorating/ dying person to their preferred place of care, are often heard. It can be incredibly rewarding to facilitate this process. Do it well and you will always be remembered; do it badly and you will never be forgotten!

Active listening allows the HCP to pick up on cues, repeat back what they have heard, check whether they have understood and be brave enough to give honest replies to the questions they will invariably be asked if the patient trusts them.

Example Box 6 active listening:

Patient *" I'm so fed up with all this fuss, it's exhausting"*

HCP *"all this fuss - pause… would you like to tell me a bit more about what that means? " wait for reply which might include some silence*

Patient *" Well I don't think I'm making any improvements. I'm tired all of the time and I'm losing weight despite the awful tasting supplements. I just feel like giving up"*

HCP *"Giving up?" silence*

Patient *"yeah, stop all the treatments that aren't making a difference"*

HCP *"so it sounds like you have given this a lot of thought. Can I ask if there is anything you are particularly concerned about?" silence*

Patient *"well there's the obvious question……"*

HCP *" go on"*

Patient *"how long have I got?"*

HCP *"can I just check what are asking me - how long you have left to live?"*

Patient *"Yes"*

HCP *"well I can understand why you're feeling you are not making improvements and I can see that too. It's not easy to say with any certainty exact timings but I do think you are entering your last months of life….."*

Things to do and think about: Repositioning at end of life

Why is it that we think a person nearing the end of their life can't be repositioned? Is this a myth or unconscious bias (Picture 1)? Do we have a preconceived notion that this will cause distress, or it is no longer required? Repositioning for comfort is a very important element of end-of-life care. We have spent our entire life moving around in bed so why should end of life be different? The skin is the biggest organ of our body and skin failure occurs as the body shuts down as part of the dying process, so caring for skin integrity deserves as much attention as any other aspect of symptom control. Terminal agitation could be a direct result of being uncomfortable from being in the same position too long and the person may not be able to communicate this verbally due to altered conscious state.

If repositioning is likely to cause distress firstly understand the cause of this - it may be pain/anxiety/nausea. Ensure regular medication for such symptoms is optimised, this may require a medication review by a Doctor or pain specialist. Before carrying out a repositioning intervention consider providing this medication prophylactically. In a community setting this may involve phoning ahead of scheduled visits to prompt this. This is where teamwork comes into play so that care is joined up and everyone involved communicates with each other to get the best outcome for each person at end of life.

Picture 1: Unconscious bias (Vora, 2023)

Ensure repositioning for comfort is assessed at every available opportunity if at home or in a health or social care facility. If at home this may be each time a carer or HCP visits.

How frequently to reposition a person at end of life is a commonly asked question. Repositioning is a prescription of care and pressure ulcer risk assessment and outcomes from skin inspections will support this decision-making. At end of life, these principles still apply but with an *as frequently as able* approach following optimisation of symptom control. This may include educating family members on how to deliver this and an understanding that long periods of no repositioning may make the actual reposition more painful due to muscle stiffness.

In some instances it may be the family members concern or anxiety around repositioning their loved one that discourages the health or social care professionals from repositioning. Education on the risks and consequences of pressure ulcers and repositioning for comfort should be provided.

Pressure ulcers are painful and reduce quality of life. Pressure ulcer prevention remains a key priority even at end of life. Prevention is still the best option and if a pressure ulcer is prevented, the more comfortable the patient will be. If it would matter to someone you love, it will matter to whoever you are caring for, no matter what the setting.

Use SPIKES (Baile et al., 2000) as a communication aide memoir to help understand what the patient knows already and what information they want to know as opposed to what information we as HCPs think they need. Give the patient autonomy and agency to make their own decisions based on information that is tailored to their understanding (e.g., providing easy read information to someone with a learning disability).

Advance care planning is essential to prevent unwanted admission to Accident & Emergency and / or unwanted treatment and yet this occurs regularly in the last 3 months of life (Pask et al., 2022). With more people than ever dying at home (Raleigh, 2021), more emphasis is needed to ensure staff have the right skills and experience to discuss future planning with people in their care. However, this is often fraught with the challenges of pressure of work and lack of staff and thus, resilience in teams resulting in areas of care that

aren't essential on the day /time of the visit not being fully addressed. The consequences of not having these discussions may have enormous ramifications for quality of life however, so these conversations are just as important as any other aspect of care. If these types of discussions are left until the person has lost capacity, then HCPs default to best interest decisions, but how are those understood if they haven't been asked what those entail? Family, carers and friends can (and should) of course be spoken with, but paternalism ensues and the principles of "no decision about me without me" can then be overlooked. Remember, family and friends know the person better than you. Involve them.

The ReSPECT Form (Resuscitation Council UK) aids a better conversation around what is and isn't acceptable to patients who are identified as being in their last year of life. It is person centred and is unique to each person. It allows for cultural considerations to be included (refusal of some treatments if it is against their beliefs, religion for example). It can highlight whether more in-depth, legally binding Advance Decision to Refuse Treatment is required. Follow the Universal Principles of Advance care planning (NHS England, 2022c).

Universal Principles for Advance Care Planning

1. The person is central to developing and agreeing their advance care plan including deciding who else should be involved in the process.

2. The person has personalised conversations about their future care focused on what matters to them and their needs.

3. The person agrees the outcome of their advance care planning conversation through a shared decision-making process in partnership with relevant professionals.

4. The person has a shareable advance care plan which records what matters to them, and their preferences and decisions about future care and treatment.

5. The person has the opportunity, and is encouraged, to review and revise their advance care plan.

6. Anyone involved in advance care planning is able to speak up if they feel that these universal principles are not being followed.

Critical Care

What is Critical Care?

Critical care is now used as the term that encompasses 'intensive care'(ICU) 'intensive therapy' and high dependency units.

Critical care is needed if a patient needs specialist monitoring, treatment and attention, for example, after routine complex surgery, a life-threatening illness or an injury. If someone needs critical care, they can be said to have a critical illness (NICE, 2009b) and have conditions that require specialist monitoring, treatment and attention.

Critical care units (CCUs) are specialist hospital wards that treat patients who are seriously ill and need constant monitoring. These patients might, for example, have problems with one or more vital organ or be unable to breathe without support.

CCUs are staffed by specially trained HCPs who deliver intensive levels of care often with one nurse for every one or two patients (Anandaciva, 2020). Patients in these units are closely monitored and supported by sophisticated equipment, including ventilators that help patients breathe.

The higher staff numbers within CCUs may initially be alarming for patients and their loved ones, however, this level of staff to patient ratio is necessary due to the nature of care required. Brindle et al. (2013) identify that Critical Care patients are a high risk population, and that being too unstable to reposition contributes to the higher incidence of pressure ulcer.

Patient scenario:

45 year old male admitted with C4 spinal cord injury requiring support from a ventilator. His injury was managed conservatively with a hard collar for 6 weeks. He had significant issues with neuropathic pain and discomfort from the collar when positioned in full 90 degree side lying tilt position. He often refused repositioning because of this, and despite discussions about skin care, he often said it didn't matter because he couldn't feel anything anyway. He was able to tolerate 3 hourly log rolls and being positioned back into supine. After repeated verbal education about pressure relief and the consequences of developing a pressure ulcer from all members of the multi-disciplinary team, and discussion with the patient about what was achievable, the plan was changed to allow 1 hourly repositioning into left or right side lying 60 degrees. The positioning plan was documented on the electronic patient record but also on a white board in the patient's bed space where it was visible to him, and all members of the team. The consistency of the conversations from all members of the team in educating this patient about his newly acquired increased risk of skin damage and the consequences of any skin breakdown, and the visibility of information, allowed this patient to fully participate in his care and be provided with the information to make an informed and shared decision. The process of repositioning was the one aspect of care he could exert control over, and his initial refusal was a way for him to exhibit this control. Following discussion and actively listening to this patient and his concerns, a solution of 1 hourly position time for side lying was achieved and adhered to.

Steps to supporting concordance and shared decision-making – a summary

Having read this you will now have some tools to use in your own organisation to work towards person centred care and shared decision-making. Improving this will support concordance.

Things to do and think about:

Consider

1. Is the culture in your organisation/department/team enabling shared decision-making? How to test this, what to do if it's not.

2. What aids can you use to support staff to have SDM conversations? How can PDA, SPIKES and motivational interviewing be introduced?

3. How staff are supported to be clinically curious

4. What are the training needs for the organisation/department/team?

5. When the person declines interventions how the conversation and care plan develop from there. Have all options and compromises been considered? Is this their final answer? How to consider when to revisit the conversation. How to document this?

6. How to keep staff safe should harm occur because of refusal.

7. What processes and documentation the organisation has in place to support staff fully and share the risk.

An example of what to consider when an alternating pressure mattress is being offered to a person

Supporting a person to consider the use of an alternating pressure mattress

Person identified as at risk of PU

Risk factor includes immobility

Culture
Organisational
Department
Team
Individual

The benefit of an APM has been identified?

Ascertain desire to understand and be involved in decision making

Be aware of local policy, guidance and resources

Discussion with person/ family/carers about risk level. Include the risk assessment, benefits and consequences

Is there a culture to support person-centredness?

Accepts mattress

Wants more information/ refuses mattress/unsure

Culture assessment

Patient Decision Aid
Risks/benefits/ consequences
Facts and figures

Offer more information including
Risks • Benefits • Consequences • Facts & Figures
Alternatives & Compromises
If refusing explore why

Are there any concerns about the organisations culture?

Escalate concerns via chain of management

Use SPIKES and SURETY
Motivational Interviewing and clinical curiosity to support conversation

Person still refuses and does not accept an alternative

Use Freedom to Speak Up Guardians/Ambassadors if concerns are ignored

Staff training requirements

Document conversation including their reasons for refusal (if known) and what alternatives were offered and accepted/not accepted
Communicate these reasons at handover opportunities

Agree with them that the conversation will be revisited (agree timescale) and let them know they can change their mind anytime
Advise them what to look out for to notice skin changes early and what other interventions staff would like to do to compensate for lack of mattress

Conclusion

Concordance is a mutual journey between the HCP and the person receiving care. It is multilayered and influenced by many factors. It is not a final destination and if a person is making-decisions that seem unwise to the HCP they are never the less that person's decisions to make. This does not make them non-concordant or non-adherent or difficult. It simply means that, based on the information they have been given, in line with their core values, beliefs and experiences, they choose not to accept a certain PU prevention intervention. As HCPs our role is to ensure we have provided them with adequate, unbiased information that has helped them reach their decision. We must know our field and be able to offer alternative options that may support them in a way that is more preferable to them. Labelling them as non-concordant can create a bias in staff towards that person that means their decisions are not respected, compromises and alternatives are not considered and conversations are not revisited.

This document has attempted to explore the complicated issue of concordance, person centred care and shared decision-making in relation to the prevention of pressure ulcers. It is hoped that the reader has been able to relate to the concepts discussed and can take these further to explore the issue in their own organisation.

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