End of Life Care for Adults

Policy number and category	C22	Clinical
Version number and date	Version 1	November 2022
Ratifying committee or executive director	Clinical Governance Committee	
Date ratified	November 2022	
Next anticipated review	November 2025	
Executive director	Executive Director of Quality and Safety (Chief Nurse)	
Policy lead	Lead Nurse for Physical Health	
Policy author *(if different from above)*	As Above	
Exec Sign off Signature (electronic)		
Disclosable under Freedom of Information Act 2000	Yes	

Policy context

- The aim of this policy is to provide staff with a framework, clear direction, and standards, to deliver planned, compassionate, and competent person-centred care for patients as they approach and reach the end of their life.
- As a large mental health trust, we have a role to play in supporting our service user [with our external partners], to ensure they have the right care and the right time in the right place – which may be one of our inpatient units

Policy requirement (see Section 2)

- End of life care is tailored to the needs, wishes and preferences of the dying person, their family and those identified as important to them
- It is led by a senior responsible doctor and a lead responsible nurse, who can access support from specialist palliative care services as needed
- It is delivered by a clinical team and others who have the skills, knowledge and support needed to care for dying people and their families
- It includes assessment of the person's condition whenever that condition changes and timely and appropriate responses to those changes
- It includes regular and effective communication using the ReSPECT process between the dying person and their family and our staff, and between partner organisations
- It provides tools and pathways which will support decision making as someone is moving towards the end of their life

Contents

1. Introduction

Providing end of life care should be an integral part of every health care worker's role and is an integral part of our trust values. However, the expected death of a patient in the care of BSMHFT is not a regular event so it is even more important that staff have the knowledge, skills, and support, to deliver effective care and treatment to patients who are approaching the end of their life.

Death is inevitable and does not necessarily constitute a failure of care. Indeed, caring for those approaching the end of life is one of the most important and rewarding areas of care. Although it is challenging and emotionally demanding, if staff have the necessary knowledge, skills, and attitudes, it can be immensely fulfilling.

Good end of life care enables people to live in as much comfort as possible until they die and to make choices about their care. It is about providing support that meets the needs of both the person who is dying, and the people close to them, and includes management of symptoms, as well as provision of psychological, social, spiritual, and practical support. Care does not end at death but includes appropriate care of the body and support for any family and carers.

This policy is solely concerned with planned end of life care and does not apply to unexpected or sudden deaths.

1.1. Rationale (why):

1.1.1. This policy is related to the palliative and end of life care needs of BSMHFT service users with co-existing physical illnesses which are life shortening or terminal.

1.1.2. The palliative and end of life period which may extend to many months or years; therefore, this policy aims to improve the care service users receive from the point of a terminal/life-shortening diagnosis until their death and beyond into the bereavement phase whilst in our care.

It includes

a. The care which service users can access from partner organisations.
b. The processes that we must support easier access to specialist services

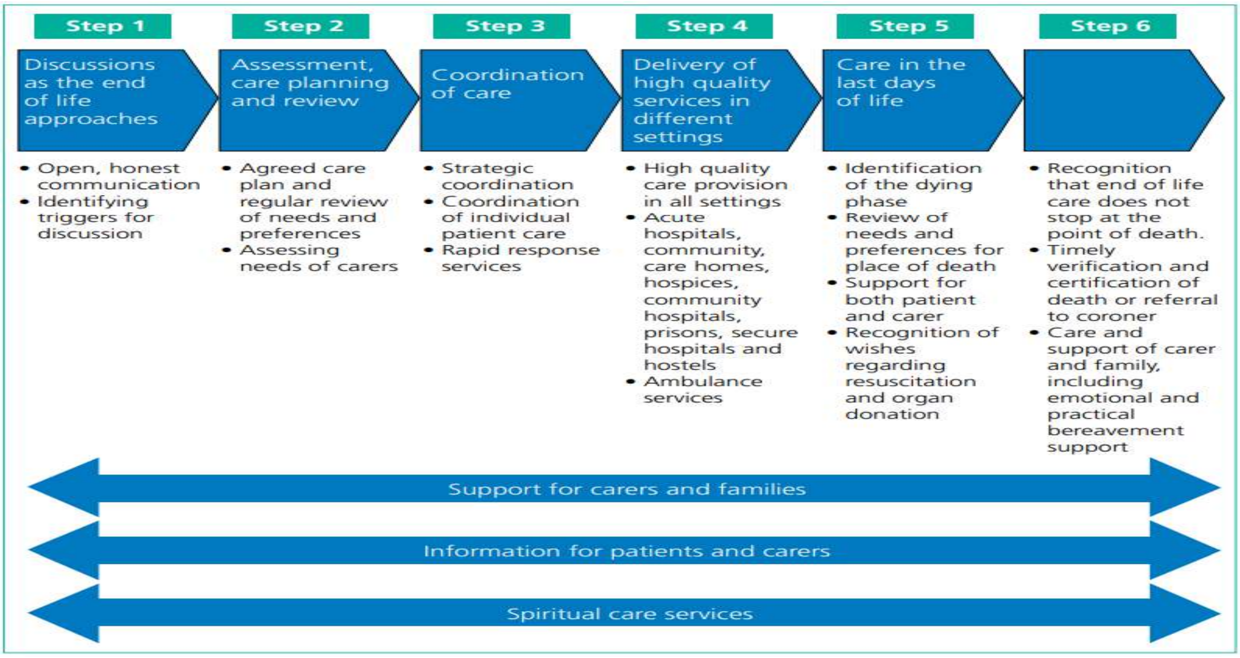
1.1.3. This policy should be read in conjunctions with

- BSMHFT Our Commitment to Palliative and End of Life Care 2021-2025
- NICE guidelines (National Institute for Health and Care Excellence (NICE), 2019) (National Institute for Health and Care Excellence (NICE), 2011) (National Institute for Health and Care Excellence, 2017) (National Institute for Health and Care Excellence (NICE), 2015)
- DoH End of Life Care Strategy 2008 (Department of Health, 2008)
- West Midlands Palliative Care Guidance **www.westmidlandspallcare.co.uk**
- National Palliative and End of life care partnership 2015
- Birmingham, Sandwell, Solihull and enirons APC Formulary (Birmingham, Sandwell, Solihull and environs APC Formulary, 2021)

1.2. Scope

The definition of the beginning of end-of-life care is variable according to individuals own personal and professional perspectives. In some cases, it may be the person who first recognises its beginning. In other cases, the principal factor may be the judgement of the clinical team responsible for the care of the person. In all cases, subject to the person's consent, the beginning is marked by a comprehensive assessment of supportive and palliative care needs.
It is important to consider the support, care and information that are required by the person's family and caregivers both during the illness and into bereavement. Similarly, spiritual care and support for both the person and their carers is integral to the end-of-life care pathway

The End-of-Life Care Pathway (Department of Health, 2008)



Particular attention must be made regarding Prison Healthcare services. Policy writers should ensure that if there is any reason why the policy may not apply or if variation of the policy is required by the Prison that this is explicitly highlighted.

1.3. Principles (beliefs):

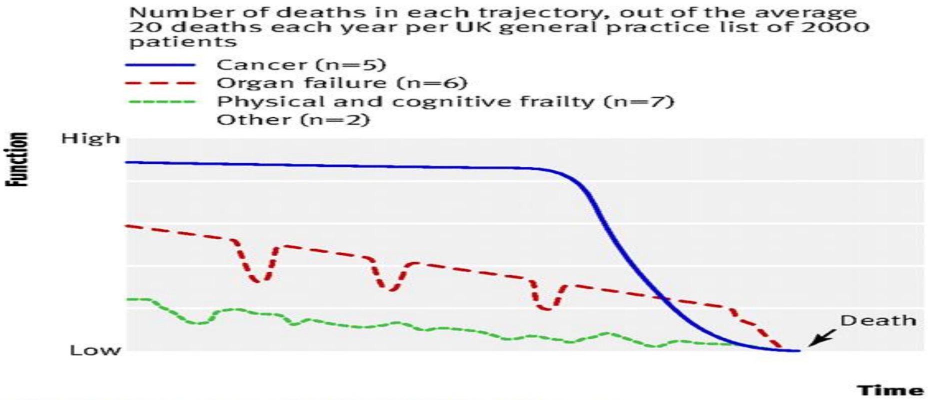
1.3.1. People approaching the end of life are identified in a timely way. The General Medical Council (General Medical Council, 2010) defines approaching the end of life as when a person is likely to die within the next 12 months. This information is available on the GP GSF register for those managed in the community

1.3.2. This timeframe provides a guide as to when people might be identified as approaching the end of life. For some conditions, the trajectory may require identification and subsequent planning can happen earlier. For other conditions, it may not be possible to identify people until nearer the time of death.

1.3.3. Some people with long term conditions remain in reasonably good health until shortly before their death, with a steep decline in the last few weeks or months of life. Others will experience a more gradual decline, interspersed with episodes of acute ill health from which they may, or may not, recover.

1.3.4. A third group are very frail for months or years before death, with a steady progressive decline. Identification should take place with sufficient time to enable provision of high-quality end of life planning, care, and support in accordance with the person's needs and preferences. Identification needs to be considered on an individual basis as no two people will have an identical end of life care pathway.

The three main trajectories of decline at the end of life (Murray & Sheikh, 2008)



Scott A Murray, and Aziz Sheikh BMJ 2008;336:958-959

1.3.5. The Trust positively supports individuals with a mental health diagnosis and learning disabilities and/or autism and ensures that no-one is prevented from accessing the full range of mental health and end of life services available.

1.3.6. Staff will work collaboratively with colleagues from learning disabilities services and other end of life organisations, to ensure that service users and carer’s have a positive episode of care whilst in our services. Information should be shared appropriately to support this.

2. **The policy**

It is the policy of Birmingham and Solihull Mental Health NHS Foundation Trust that service users in our care will receive end of life care which is tailored to their needs, wishes and preferences.

- End of life care is tailored to the needs, wishes and preferences of the dying person, their family and those identified as important to them
- It is led by a senior responsible doctor and a lead responsible nurse, who can access support from specialist palliative care services as needed
- It is delivered by a clinical team and others who have the skills, knowledge and support needed to care for dying people and their families
- It includes assessment of the person’s condition whenever that condition changes and timely and appropriate responses to those changes
- It includes regular and effective communication between the dying person and their family and our staff, and between partner organisations
- It provides tools and pathways which will support decision making as someone is moving towards the end of their life

- It is documented on the recognised ReSPECT assessment form (Appendix 4) by a practitioner suitability trained and qualified to complete it

3. The procedure

3.1. Service Delivery

3.1.1. Assessing the need of the person and their carers

3.1.2. People approaching the end of life are identified in a timely way. The General Medical Council (General Medical Council, 2010) defines approaching the end of life as when a person is likely to die within the next 12 months.

3.1.3. When this is recognised, the staff should consider all the well-being needs of the service user to support them at the end of their life.

3.1.4. To support the assessment and the decision, there are useful tools which can support and are approved by the trust for the End-of-Life planning for our service users.

3.1.5. They should be used as part of a clinical assessment, risk assessment, ongoing referrals and development or reviewing the ReSPECT assessment.

- Supportive and Palliative Care Indicators Tool (SPICT™) – Appendix 2
- Rockwood Clinical Frailty Scale – Appendix 3

3.2. Communication and shared decision-making

3.2.1. The definition of the beginning of end-of-life care is variable according to the individuals personal and professional perspectives. In some cases, it may be the person who first recognises its beginning. In cases the principal factor may be the judgement of the clinical team responsible for the care of the person. In all cases, subject to the person's consent, the beginning is marked by a comprehensive assessment of supportive and palliative care needs.

3.2.2. It is important to consider the support, care and information that is required by the person's family and caregivers both during the illness and into bereavement.

3.2.3. Similarly, spiritual care and support for both the person and their carers is integral to the end-of-life care pathway

3.2.4. The reality of death and dying is rarely discussed in modern society. Evidence suggests most find it hard to engage in advance with the way in which they would like to be cared for at the end of their life.

3.2.5. A lack of openness and discussion about death and dying will cause people to have unnecessary fears about the process of dying

3.2.6. We will also need to be aware of the service users wishes and therefore how best to help and support them physically, psychologically, spiritually, and socially

3.3. Providing individualised care

3.3.1. All service users approaching the end of life, and their carers should be entitled to: -

3.3.2. Their needs assessed by a professional or professionals with appropriate expertise

3.3.3. Have a care plan and ReSPECT form (which records their preferences and the choices they would like to make). The care plan should be reviewed as their condition changes

3.3.4. Be involved in decisions about treatments prescribed for them, including the option to say ‘no’ to treatments they do not wish to have prescribed.

3.3.5. Service users should know that systems are in place to ensure that information about their needs and preferences can be accessed by all relevant health and social care staff [with their permission.]

3.3.6. Care plans, including the person’s preferences, wishes and views on resuscitation, should be available to all who have a legitimate reason to access them, including urgent care. This should be established as early as possible, so any resources are co-ordinated in a timely manner; however, a person’s participation in care planning (including advance care planning) is voluntary.

3.3.7. Identify and document in advance any spiritual, cultural, or practical wishes the service user and their family/carers may have for the time of death or afterwards, particularly regarding the wish for urgent release for burial or cremation. This can be done as part of the advance care planning process, or it can be completed nearer the point of death.

3.3.8. Information related to spiritual care needs is available on connect.

3.3.9. Staff should ask the person (if this is possible and/or appropriate) who they wish to be present at the time of their death. If this is not possible from the service user, we should try to find out from the family/carers, as well as details of how they wish the news of the death to be communicated if they are not present. Relatives contact details will need to be recorded in Rio and readily accessible to all appropriate staff.

3.3.10. To make these choices the service user needs capacity. See 3.13

3.3.11. No pressure should be brought to bear by staff, family or any organisation on the individual concerned to take part in advance care planning.

3.3.12. During the course of discussions, it may become apparent that the person wishes to make an Advance Decision to Refuse Treatment (ADRT) i.e., a refusal of a specific treatment or intervention. This decision only applies at a future time when that person lacks capacity to consent to, or refuse, the specified treatment. This is set out in section 24 (1) of the Mental Capacity Act. Specific rules apply to advance decisions to refuse life-sustaining treatment (see 3.13)

3.3.13. Advance care planning should include asking whether the service user has a ‘Lasting Power of Attorney’ which allows the person to nominate an Attorney(s) to manage their finances and affairs should they lose capacity in this respect.

3.3.14. This should be recorded in the service users care plan in Rio/care records and Respect form for all the members of the multiprofessional care team to review, to be shared with the service user and those most important to them.

3.3.15. Whilst it is normally possible and desirable to meet the wishes of a dying person, when this is not possible it is important to explain the reason why to the person and those important to them.

3.3.16. If advise and support is required, contact palliative care support in Appendix 7

Addendum – *** there is an advance statement template available on Rio in the Mental Health Legislation section; however, there is no consensus which tool is used for advance statements/care plans.
Other useful links can be found Advance statement about your wishes - NHS (www.nhs.uk)
advance-care-planning-quick-guide.pdf (nice.org.uk)

The tools to support with care plans are available: -

- Rockwood Clinical Frailty Scale supports the evaluation of the care which is needed depending on the frailty of the service user. See Appendix 3
- Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) – see Appendix 4 (see 3.4)
- Treatment Escalation Protocol – see Appendix 5

3.4. ReSPECT key principles, processes, and tool

3.4.1. ReSPECT is relevant to decisions about cardiopulmonary resuscitation (CPR), as well as decisions relating to other emergency and potentially life-sustaining treatments, such as clinically assisted hydration and nutrition, assisted ventilation and intravenous antibiotics (this list is not exhaustive).

3.4.2. Is intended to be transferable between, and valid in, all healthcare settings, to avoid duplication, and to ensure that the person remains at the centre of decision-making wherever they may be.

3.4.3. Is applicable to all adults, children and young people whether or not they have an existing illness, or an advanced, progressive illness.

3.4.4. Does not remove the need to record discussions and rationale for decision-making in a person's current Rio, in line with local procedures.

3.4.5. The ReSPECT document is a summary document that facilitates recording and sharing of important information.

3.4.6. Is intended to replace forms currently in use to record 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) decisions and 'Emergency Treatment Plans' related to end of life care. However, it is acknowledged DNACPR forms will still be in existence for some time and do not conflict with this policy. In time, these DNACPR forms will be replaced by ReSPECT forms.

3.4.7. The ReSPECT conversation and completion of the form is only to be done by medical staff (FY2 and higher) and advance clinics staff (ANP level) who have undertaken appropriate recognised 'RCUK ReSPECT' training

3.4.8. To have competency, staff must be able to understand and answer the psychological and physiological questions. The ReSPECT form should then be endorsed by the clinician responsible for the person's care, i.e., their consultant, GP, or appropriate deputy within 7 days.

3.4.9. When a service user is admitted to an inpatient unit within the trust and has a DNACPR document or ReSPECT form in place, it should be reviewed, **within 7 days** of admission. This ideally should be a new conversation with the patient and/or their advocate. This conversation must be discussed at the next MDT which including the senior clinician with overall responsibility or their appropriate duty.

3.4.10. When undertaking a conversation about the ReSPECT process, a capacity assessment must be undertaken specific to this decision for all service users, with signposting to the mental capacity form on Rio documented on the ReSPECT form.

3.4.11. When visiting a patient within the home, all BSMHFT staff should acknowledge and adhere to the wishes expressed on the ReSPECT form and liaise with the community services for advise and support if needed.

3.5. Monitor and Review

Using the knowledge and information from the full assessment and information gathered from the multiprofessional team, the service user and those important to them will determine whether the person is deteriorating, stable or improving.

3.6. Recognising and identifying when a person may be in the last days, weeks, or months of life

When the person is entering the last few days, weeks, or months of life it is vital the care provided is only to support a good end of life which will include spiritual, emotional and symptom management (as opposed to health promotion or prolonging)

3.7. Managing symptoms

3.7.1. Providing appropriate non-pharmacological methods of symptoms management is an important part of high-quality care at the end of life.

3.7.2. These can be agreed and may include re-positioning to manage pain, fans to help with breathlessness feeling, relaxation techniques, touch techniques or soothing music.

Other areas of support may include the following

- Psychological support
- Family visits
- Support groups – charity
- Anxiety and breathlessness groups
- Consider referral to physiotherapy, occupational therapy for difficulties with activities of daily living

Clear care plan (for the service user and for those important to them) and a ReSPECT assessment (Appendix 4) and/or an advanced care plan
Useful links can be found in 3.8

3.8. Principles for managing medicine

- When it is recognised that the service user may be entering the last days of life, there must be a review of their current medicines. Following discussion and agreement, those which are of no value in providing symptomatic benefit or may cause harm should be stopped. (deprescribing)

- Involve the service user and those important to them to make a decision about symptom control in the last days of life:
- Use the individualised care plan to help decide which medicines are clinically appropriate.
- Discuss the benefits and harms of any medicines offered, including diabetes medication (TREND Diabetes, 2021), cardiovascular or medication which may no longer add therapeutic value.

When considering medicines for symptom control, review WMPC Palliative Care Guidelines (West Midlands Palliative Care Physicians, 2020), (West Midlands Palliative Care, 2021) West Midlands Palliative Care – Guidance, Research, Education and Events (westmidspallcare.co.uk) take into account:

- the likely cause of the symptom
- the service users' preferences alongside the benefits and harms of the medicine
- any individual or cultural views that might affect their choice
- any other medicines being taken to manage symptoms
- Any risks of the medicine that could affect prescribing decisions, for example prescribing cyclizine to manage nausea and vomiting may exacerbate heart failure.

Decide on the most effective route for administering medicines in the last days of life tailored to the dying person's condition, their ability to swallow safely and their preferences.
Consider prescribing different routes of administering medicine if the dying person is unable to take or tolerate oral medicines.
Consider the need to use a syringe pump to deliver medicines for continuous symptom control if more than 2 or 3 doses of any 'as required' medicines have been given within 24 hours.
Regularly reassess, at least daily, the dying person's symptoms during treatment to inform appropriate titration of medicine.
At this stage, seek specialist palliative care advice from the specialist service (including the specialist palliative care pharmacist) involved in the dying person's care. If the symptoms do not improve promptly with treatment or if there are undesirable side effects, such as unwanted sedation, the prescription will need to be updated.
Appendix 8-14 provides the recommended guidance from the West Midlands Palliative Care prescribing guidelines (correct November 2022). As a trust we should expect our service users to receive the same pharmacological management as those in other clinical setting or within their own home.

The clinical teams should refer to these guidelines when prescribing end of life medication and practitioners should refer to this web site and Birmingham, Sandwell, Solihull and eviron APC Formulary for any updates (Birmingham, Sandwell, Solihull and environs APC Formulary, 2021) and Specialist Palliative Care guidelines (West Midlands Palliative Care Physicians, 2020)
They are broadly sectioned in the following subheadings

- Anxiety, Delirium, Restlessness and Agitation
- Breathlessness (Dyspnoea)
- Noisy respiratory secretions
- Nausea and vomiting
- Pain
- Supporting hydration

3.9. Care and support of service users across all points on the care pathway

3.9.1. Once a care plan has been agreed and the ReSPECT process has commenced, it is essential that all the services which the person needs are effectively co-ordinated. Although the ReSPECT process is documented, it can be flexible to any wishes or need changes

3.9.2. People may require services from multiple agencies or in different settings at different time.

3.9.3. Staff need to have knowledge of which services are available to support the service users, carer, and our trust staff.

3.9.4. Consider reviewing information via the electronic information-sharing record system

3.9.5. Consider involvement from

- The service users own GP (or the trust GP in secure sites)
- District nurses
- Pan Birmingham Palliative Care Network
- Local hospice care
- Social Care

Link to their referral form and contact details is available in Appendix 6 and 7 and on Connect End of Life pages End of Life - End of Life (sharepoint.com)

3.10. Relationship and communication

3.10.1. Work in partnership with the service user and their families or carers. Offer help, treatment, and care in an atmosphere of hope and optimism.

3.10.2. Take time to build trusting, supportive, empathic, and non-judgemental relationships as it is an essential part of the care.

3.10.3. Aim to foster their autonomy, promote active participation in treatment decisions and support self-management

3.10.4. Maintain continuity for an individual therapeutic relationship

3.10.5. Offer access to a trained advocate if needed.

3.10.6. Ensure that you are easily identifiable (for example, by wearing appropriate identification) and that you are approachable

3.10.7. Always address the service users using the name and the title they prefer

3.10.8. Clearly explain any clinical language and check that the service user understands what is being said

3.10.9. Consider communication needs, including those of people with learning disabilities, sight or hearing problems or language difficulties and provide independent interpreters (that is, someone who does not have a relationship with the service user) or communication aids (such as using pictures, symbols, large print, Braille, different languages, or sign language).

3.10.10. When working with our service users

- make sure that discussions take place in settings in which confidentiality, privacy and their dignity is respected
- Be clear with service users about who will be reviewing their care. Explain which health and social care professionals have access to information about their diagnosis and treatments and in which circumstances this information is shared.

3.11. Providing information

3.11.1. Ensure that comprehensive written information about the nature of the treatments, the services available for their condition is available in an appropriate individual format depending on their communication and language needs

3.11.2. Although BSMHFT does not have its own literature, many of the voluntary organisations and local palliative care providers can provide them to suit the individual need of the service user (examples are Hospice UK, Sue Ryder organisation, Marie Curie, MIND, Resuscitation UK ReSPECT). Consider requesting supportive information from our local palliative care providers

3.11.3. Ensure that you are:
- Utilising local and national sources (organisations and websites) of information and/or support for people
- Facilitating access for these resources
- Discussing and actively supporting service users to engage with these resources.

3.12. Avoiding stigma and promoting social inclusion

(Jedwood, Phimister, Ward, Holliday, & Coad, 2018)

When working with a service user with a mental health illness:

3.12.1. Consider that stigma and discrimination are often associated with a mental health diagnosis in the wider community

3.12.2. Be respectful of, and sensitive to the service users' gender, sexual orientation, socioeconomic status, age, background (including cultural, ethnic, and religious background) and any other disability

3.12.3. Be aware of possible variations in the presentation of people at the end of their life with a mental health problem and adapt communication style to support them

3.12.4. All staff supporting our service users with a mental health diagnosis at the end of their life should have the skills to:
- Provide an appropriate assessment, using varying communication tools for people from different cultural, ethnic, religious, or other diverse backgrounds
- To address cultural, ethnic, religious, or other differences in treatment expectations.

3.13. Involving families and carers

The term 'families' is broad and relates to any person who has significant contact with the person approaching the end of life, including children, a partner, or close friends.

3.13.1. Support for families and carers may include emotional and psychological support. Training on practical issues should be available for those caring for people approaching the end of life who require extra help. Support may also encompass planning for other circumstances, for example when carers are taken ill.

3.13.2. The emphasis here is on support being offered to carers. The right of carers to refuse support must be respected. Carers who decline support initially should be offered the opportunity to change their minds later if they wish.

3.13.3. Discuss with the service user if and how they want their family or carers to be involved in their care and those who have ‘lasting power of attorney’. Such discussions should take place regularly to take account of any changes in circumstances and should not happen only once.

3.13.4. The involvement of families and carers can be quite complex, staff should act to work with families and carers, and in managing issues relating to information sharing and confidentiality.

3.13.5. If the service user wants their family or carers to be involved, encourage this involvement:

3.13.6. Agree between the service user and their family or carers about confidentiality and sharing of information on an ongoing basis

3.13.7. Explain how families or carers can help support the service user and help with treatment plans

3.13.8. Ensure that no services are withdrawn because of the family's or carers' involvement unless this has been clearly agreed with the service user and their family or carers.

3.13.9. If the service user wants their family or carers to be involved, give the family or carers verbal and written information about:

- statutory and third sector, including voluntary, local support groups and services specifically for families and carers, and how to access them
- Their right to a formal carer's assessment of their own physical and mental health needs, and how to access this

If the service user does not want their family or carers to be involved in their care:

3.13.10. Seek consent from the service user, and if they agree give the family or carers verbal and written information on their decision

3.13.11. Give the family or carers information about statutory and third sector, including voluntary, local support groups and services specifically for families or carers, and how to access these

3.13.12. Tell the family or carers about their right to a formal carer's assessment of their own physical and mental health needs,

3.13.13. Have awareness that service users may be ambivalent or negative towards their family for many different reasons, including due to their historic mental health condition or because of prior experience of difficulties (including violence, abuse etc.)

3.13.14. Ensure that service users who are parents with caring responsibilities receive support to access the full range of mental health and social care services, including:

- information about childcare to enable them to attend appointments, groups, and therapy sessions
- hospital care in local mother and baby units for women in the late stages of pregnancy and within a year of childbirth
- A family room or space in inpatient units where their children can visit them.

3.14. Decision, capacity, and safeguarding

Clinical staff should liaise with the responsible clinician to ensure that they:

3.14.1. Understand and can apply the principles of the Mental Capacity Act (2005) (legislation.go.uk, 2005) appropriately

3.14.2. Are aware that mental capacity needs to be assessed for each decision separately

3.14.3. Can assess mental capacity using the test in the Mental Capacity Act (2005)

3.14.4. Understand how the Mental Health Act (1983; amended 1995 and 2007) (legislation.gov.uk, 2007) and the Mental Capacity Act (2005) relate to each other in practice to support the service user in the last days.

3.14.5. Develop an advance statements and advance decisions with the service user, especially if their illness is severe and they have previously been treated under the Mental Health Act (1983; amended 1995 and 2007).

3.14.6. Document these in their care plans and ensure a copy are held by the service user and is shared with any primary and secondary care partners.

3.14.7. When a service user has impaired capacity, check their care record for advance statements and advance decisions, and lasting power of attorney before offering or starting treatment.

3.14.8. If a person lacks capacity to decide, care planning and ReSPECT documentation should involve their relatives, partner, close companions, and any other care staff who know them or are responsible for their care. If the person lacks capacity and has no-one to support or represent them, staff must seek the assistance of an Independent Mental Capacity Advocate (IMCA) to represent them.

3.14.9. Consider service users for assessment according to local safeguarding procedures for vulnerable adults if there are concerns regarding exploitation or self-care, or if they have been in contact with the criminal justice system.

3.14.10. Capacity assessments (including the ReSPECT process) should be completed and documented in the Capacity Assessment form in Rio (Appendix 15 – Mental Health Legislation section- Mental Capacity)

3.15. Palliative Care for patients with Dementia

3.15.1. From diagnosis, offer people living with dementia flexible needs-based palliative care that considers how unpredictable dementia progression can be.

3.15.2. It is vital to have meaningful conversations using the ReSPECT process earlier with these service users to ensure decisions are made whilst they still have capacity

3.15.3. For people living with dementia who are approaching the end of life, use an anticipatory healthcare planning process.

3.15.4. Involve the person and their family members or carers (as appropriate) as far as possible and use the principles of best-interest decision-making if the person does not have capacity to make decisions about their care.

3.15.5. For standards and measures on palliative care, see the NICE quality standard on end-of-life care for adults. (National Institute for Health and Care Excellence (NICE), 2011)

3.15.6. For guidance on care for people in the last days of life, see the NICE guideline on care of dying adults.

3.15.7. For guidance on best interest's decision-making, see the NICE guideline on decision-making and mental capacity.

3.15.8. This quality standard provides health and social care workers, managers, service users and commissioners with a description of what high-quality end of life care looks like, regardless of the underlying condition or setting. Delivered collectively, these quality statements should contribute to improving the effectiveness, safety and experience of people approaching the end of life, and their families.

3.15.9. This quality standard describes high-quality care that, when delivered collectively, should contribute to improving the effectiveness, safety, and experience of care for adults approaching the end of life and the experience of their families and carers. This will be done in the following ways, regardless of condition or setting:

3.15.10. Enhancing quality of life for people with long-term conditions

3.15.11. Ensuring that people have a positive experience of (health) care.

3.15.12. Treating and caring for people in a safe environment and protecting them from avoidable (healthcare-related) harm.

3.15.13. The care that people approaching the end of life receive is aligned to their needs and preferences.

3.15.14. Increased length of time spent in preferred place of care during the last year of life.

3.15.15. Reduction in unscheduled care hospital admissions leading to death in hospital

3.15.16. Reduction in deaths in inappropriate places such as on a trolley in hospital or in transit in an ambulance.

3.15.17. Enhancing quality of life for people with care and support needs.

3.15.18. Delaying and reducing the need for care and support.

3.15.19. Ensuring that people have a positive experience of (social) care and support.

3.15.20. Safeguarding adults whose circumstances make them vulnerable and protecting them from avoidable harm

4 Responsibilities

Post(s)	Responsibilities	Ref
All Staff	Follow the End-of-Life procedures and care planning for patient at the end of their lives	
Service, Clinical and Corporate Directors	Complete appropriate documentation and specialist referrals in a timely manner	
Policy Lead	Ensure that managers are aware of and comply with the policy and supported in enforcing the policy with staff, including bank, agency, and staff on temporary contracts	
Executive Director	Ensure that appropriate and realistic targets are met regarding the appropriate referrals and treatments are available in a timely manner	
Others…	Well-being support is available to all staff dealing with end of life Health and Wellbeing - Health and Wellbeing (sharepoint.com)	

5: Development and Consultation process

Consultation summary	
Date policy issued for consultation	January 2022
Number of versions produced for consultation	5
Committees / meetings where policy formally discussed	Date(s)
End of Life Task and Finish group	Dec 2021, Jan 2022, April 22
Local palliative care providers	Feb 2022 and March 2022
Resuscitation UK	October 2022

Where received	Summary of feedback	Actions / Response
Diabetes service	No information related to diabetes medication	Agreed and added
Local palliative care provides	Telephone numbers changed; training opportunity available to provide to trust	Agreed and added
PCT	Review the guidelines on anticipatory medication format	Agreed

MAC	Add Statutory notification regulation 17 to appendix list	Agreed and added
Resuscitation UK	Alter Audit section to match the requirements of ReSPECT process	Agreed and added
CGC	Add link to trust values, wellbeing offer	Agreed and added
CGC	Reviewed the appendix related to COVID death *(relatives may not be able to see their loved ones again)*	Agreed this no longer applies are removed.

6: Reference documents

References

Birmingham, Sandwell, Solihull and environs APC Formulary. (2021). *Formulary Chapter 21: Palliative Care Formulary.* (M. a. Unit, Editor) Retrieved November 9, 2021, from Net Formulary: http://www.birminghamandsurroundsformulary.nhs.uk/chaptersSubDetails.asp?FormularySectionID=21&SubSectionRef=21&SubSectionID=A100

Care Quality Commission. (2013, July). Notification required by the Health and Social Car Act 2008. Guidance for English NHS providers v6. *Registration under the Health and Socail Care Act 2008*. England: Care Quality Commission. Retrieved December 14, 2021, from https://www.cqc.org.uk/sites/default/files/documents/statutory_notifications_for_nhs_bodies_-_provider_guidance_v6.pdf

Care Quality Commission. (2021, November 26). *Regulation 16: Notification of death of servic user.* Retrieved December 14, 2021, from Care Quality Commission: https://www.cqc.org.uk/guidance-providers/regulations-enforcement/regulation-16-notification-death-service-user#guidance

Department of Health. (2008). *End of Life Care Strategy Promoting high quality care for all adults at the end of life.* London: Crown publication. Retrieved October 13, 2021, from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf

General Medical Council. (2010). *Treatment and care towards the end of life: good practice in decision making.* London: GMC. Retrieved October 13, 2021, from https://www.gmc-uk.org/-/media/documents/treatment-and-care-towards-the-end-of-life---english-1015_pdf-48902105.pdf?la=en&hash=41EF651C76FDBEC141FB674C08261661BDEFD004

Jedwood, J., Phimister, D., Ward, G., Holliday, N., & Coad, J. (2018). Barriers to palliative care for people with severe mental illness: exploringthe views of clinical staff. *European Journal of Palliative Care, 25*(1), 20-25.

legislation.go.uk. (2005). *Mental Capacity Act 2005*. Retrieved October 14, 2021, from UK Public General Acts: https://www.legislation.gov.uk/ukpga/2005/9/contents

legislation.gov.uk. (2007). *Mental Health Act 2007*. (C. Publications, Editor) Retrieved October 14, 2021, from UK PUlbic General Acts: https://www.legislation.gov.uk/ukpga/2007/12/contents

Murray, S. A., & Sheikh, A. (2008). Care for all at ehe end of life. *BMJ*(336), 958-959. Retrieved October 13, 2021, from https://doi.org/10.1136/bmj.39535.491238.94

National Institute for Health and Care Excellence (NICE). (2011, November 28). *End of Life Cae for adults Quality standard [QS13] - last updated 02 September 2021*. Retrieved October 14, 2021, from NICE Guidance: https://www.nice.org.uk/guidance/qs13

National Institute for Health and Care Excellence (NICE). (2015, December 16). *Care of dying adults in the last days of life NICE guidelines {NG 31]*. Retrieved October 14, 2021, from NICE guidance: https://www.nice.org.uk/guidance/ng31

National Institute for Health and Care Excellence (NICE). (2019, October 16). *End of life care for adules:Service delivery [NG142]*. (NICE, Editor) Retrieved October 14, 2021, from NICE guidance: https://www.nice.org.uk/guidance/ng142

National Institute for Health and Care Excellence. (2017, March 2). *Care of dying adults in the last days of life Quality standared [QS144]*. Retrieved October 14, 2021, from NICE guidance: https://www.nice.org.uk/guidance/qs144

TREND Diabetes. (2021). *For Healthcare professionals: END OF LIFE GUIDANCE FOR DIABETES CARE.* TREND Diabetes. Retrieved March 25, 2022, from https://trenddiabetes.online/portfolio/end-of-life-guidance-for-diabetes-care/

West Midlands Palliative Care. (2021). *Guidelines for the use of drugs in symptom control.* (Citrus Frog) Retrieved November 11, 2021, from West Midlands Palliative Care Website: https://www.westmidspallcare.co.uk/wmpcp/guide/

West Midlands Palliative Care Physicians. (2020). *Palliative Care Guidelines for the user of drugs in symptoms control - COVID-19 Version.* West Midlands: West Midlands Palliative Care Physicians Society. Retrieved October 29, 2021, from http://www.wmcares.org.uk/wp-content/uploads/WMPCP-PalCare-Guide-Covid-Free-Version.pdf

7: Bibliography:

8: Glossary consisting of:

- **End of life** - People are 'approaching the end of life' when they are likely to die within the next 12 months although this isn’t always possible to predict and includes people whose death is imminent i.e., expected within a few days or hours
- **End of life Care** - support for people who are in the last months or year of their life to live as well as possible until they die
- **Palliative** – the term is derived from the Latin word ‘pallium’ meaning a cloak. Palliative care aims to cloak the patient’s symptoms and provide comfort even when treatments aimed at cure are no longer possible
- **Palliative Care** - focuses on the relief of pain and other symptoms and problems experienced in serious illness; the goal of palliative care is to improve quality of life, by increasing comfort, promoting dignity, and providing a support system to the person who is ill and those close to them.
- **Specialist palliative care** - is the active, total care of patients with progressive, advanced disease and [of] their families; care is provided by a multi-professional team who have undergone recognised specialist palliative care training
- **Prognostication** – predicting the likely course of a disease or ailment
- **Care plans** - documents the care and treatment actions necessary to meet a person’s needs, preferences, and goals of care. These must have been agreed with the person receiving care or by those acting in the person’s best interests.
- **Care Pathway** – is anticipated care placed in an appropriate time frame, written, and agreed by a multidisciplinary team
- **Capacity** - the ability to make a decision about a particular issue at the time the decision needs to be made or to give consent to a particular act
- **Advance Care Planning (ACP)** - a voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future and, if they wish, set on record choices or decisions relating to their care and treatment so that these can then be referred to by health professionals and family carers in the event that they lose capacity to decide once their illness progresses.
- **Advance decision to refuse treatment (ADRT)** - a decision to refuse specified treatment made in advance by a person who has capacity to do so. This decision only applies at a future time when that person lacks capacity to consent to, or refuse, the specified treatment. This is set out in section 24 (1) of the Mental Capacity Act. Specific rules apply to advance decisions to refuse life-sustaining treatment
- **Advance statements** - are written statements, either written down by the person themselves or written down for them with their agreement the person might make before losing capacity about their wishes and feelings regarding issues they wish to be considered in the case of

future loss of capacity due to illness, such as the type of medical treatment they would want or not want, where they would prefer to live or how they wish to be cared for.

- **Best interests** - under the Mental Capacity Act, any decision made, or any action done for a person who lacks capacity to make specific decisions must be in accordance with their best interests
- **Lasting powers of attorney (LPA)** - is a statutory form of power of attorney created by the Mental Capacity Act. Anyone who has the capacity to do so may choose a person (an 'attorney') to take decisions on their behalf if they subsequently lose capacity. The LPA replaces the Enduring Power of Attorney and can extend to include health and welfare as well as property and affairs
- **'Last days of life'** - is the period of time when death is imminent and when the time before the anticipated death is being measured in days
- **Responsible Clinician** - has overall responsibility for care and treatment for patients assessed and treated under the Mental Health Act. These responsibilities include, making decisions about treatment, reviewing detentions, granting leave of absence for detained patients. Although the Responsible Clinician has overall responsibility decisions about the patient's care and treatment are made in discussion with the multi-disciplinary team.

9: Audit and assurance

Element to be monitored	Lead	Tool	Frequency	Reporting Committee
NACEL audit	Clinical Effectiveness Group	NACEL audit tool	Annually	Physical Health Committee
ReSPECT Audit tool (Resuscitation Council UK)	Resuscitation committee	Review of all ReSPECT tools	Quarterly	Resuscitation committee
ReSPECT audit service evaluation and patient experience questions	Resuscitation committee	Bereavement Questionnaires	Quarterly	Resuscitation committee

10. Appendices

- Appendix 1 - Equality Analysis Screening Form assessment
- Appendix 2 - Supportive and Palliative Care Indictors Tool (SPICT™)
- Appendix 3 - Rockwood Clinical Frailty Scale
- Appendix 4 - Recommended Summary Plan for Emergency Care and Treatment (ReSPECT tool)
- Appendix 5 - Treatment Escalation Protocol
- Appendix 6 - Adult Specialist Palliative Care Referral form – Version 3
- Appendix 7 - Contact Details for Adult Specialist Palliative Care Service
- Appendix 8 - Anticipatory Medication Guidelines

- Appendix 9 - Opioid conversation: Anticipatory medication
- Appendix 10 - Algorithm for Pain in patients using Morphine Sulfate SUBCUTANEOUSLY (eGFR >30mls/min)
- Appendix 11 - Algorithm for Agitation
- Appendix 12 - Algorithm for Breathlessness
- Appendix 13 - Algorithm for Respiratory Secretions
- Appendix 14 - Algorithm for nausea and vomiting
- Appendix 15 - Mental Capacity assessment (example) on Rio
- Appendix 16 - Management of an inpatient death – managing the practicalities
- Appendix 17 - End of Life plan (inpatient units) - step by step guide
- Appendix 18 - Statutory notification Regulation 17, Care Quality commission (Registration) Regulations 2009

Appendix 1 Equality Analysis Screening Form

A word version of this document can be found on the HR support pages on Connect
http://connect/corporate/humanresources/managementsupport/Pages/default.aspx

Title of Proposal	**End of Life (adults) Policy**		
Person Completing this proposal	Lyndi Wiltshire	**Role or title**	Lead Nurse for Physical Health
Division	Corporate	**Service Area**	Trustwide
Date Started	13th July 2022	**Date completed**	13th July 2022
Main purpose and aims of the proposal and how it fits in with the wider strategic aims and objectives of the organisation.			
This policy provides a standard of care and support a service user, carer's, family, and staff will require when a service user reaching the end of their life. This covers all services within the trust			
Who will benefit from the proposal?			
All staff caring for those at the End of Life and All service users (and their wider family) at the End of Life			
Do the proposals affect service users, employees, or the wider community? ***Add any data you have on the groups affected split by Protected characteristic in the boxes below. Highlight how you have used the data to reduce any noted inequalities going forward***			
Both service user and the wider community will benefit due to an improved available service and guidelines for End of Life Care			
Do the proposals significantly affect service delivery, business processes or policy? ***How will these reduce inequality?***			
Reduce inequality for end-of-life care in our service user group			
Does it involve a significant commitment of resources? ***How will these reduce inequality?***			
It will provide the clinical staff with knowledge and resources to provide an improved service (reducing inequality) and a more dignified end of life for the service user			
Do the proposals relate to an area where there are known inequalities? (e.g. seclusion, accessibility, recruitment & progression)			

Increase accessibility for end-of-life care in our service users

Impacts on different Personal Protected Characteristics – *Helpful Questions:*

Does this proposal promote equality of opportunity? *Eliminate discrimination?* *Eliminate harassment?* *Eliminate victimisation?*	*Promote good community relations?* *Promote positive attitudes towards disabled people?* *Consider more favourable treatment of disabled people?* *Promote involvement and consultation?* *Protect and promote human rights?*

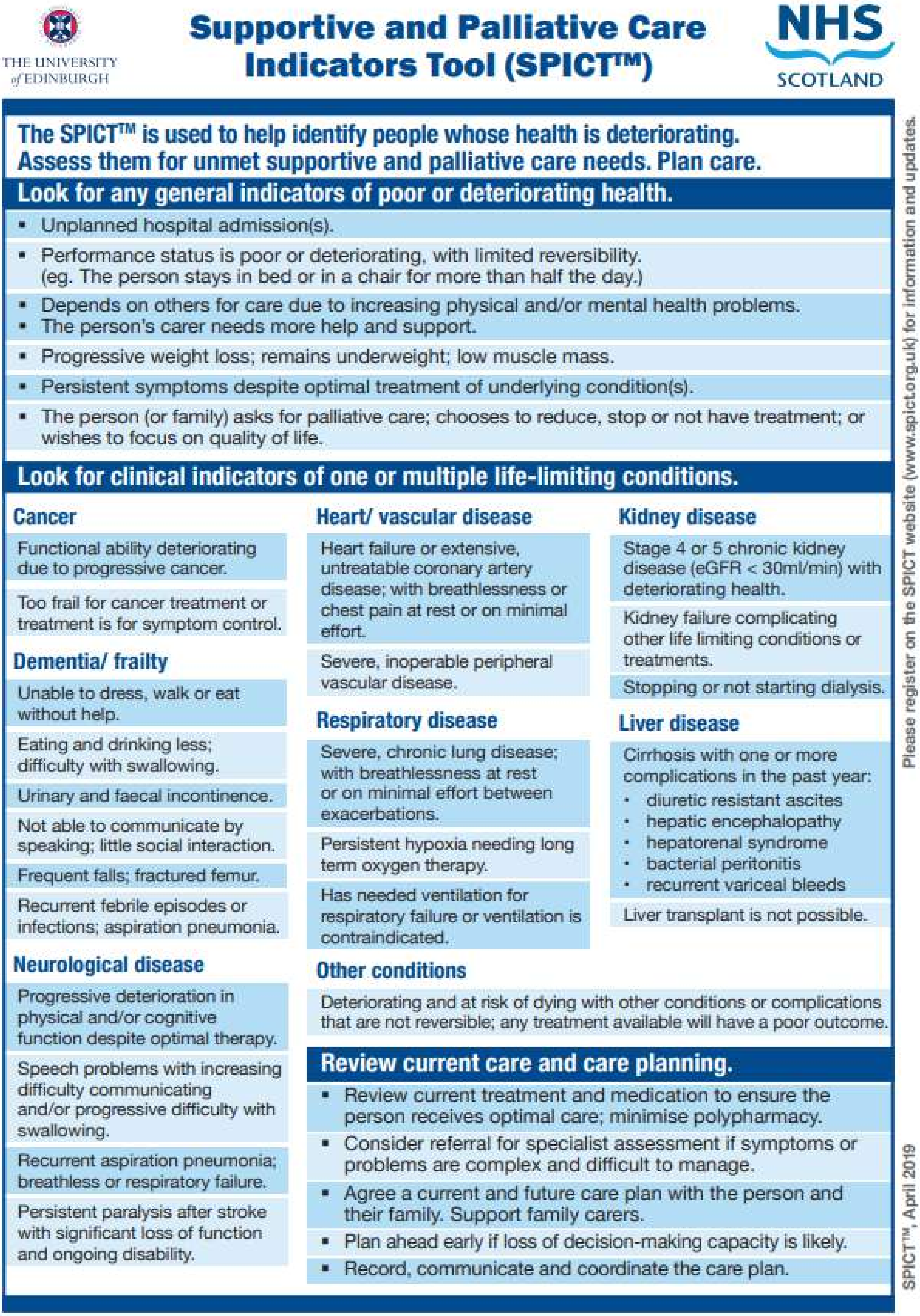
Please click in the relevant impact box or leave blank if you feel there is no particular impact.

Personal Protected Characteristic	**No/Minimum Impact**	**Negative Impact**	**Positive Impact**	**Please list details or evidence of why there might be a positive, negative or no impact on protected characteristics.**
Age			x	Resources available for those at the end of their life whilst in our services (especially inpatients)
Including children and people over 65 Is it easy for someone of any age to find out about your service or access your proposal? Are you able to justify the legal or lawful reasons when your service excludes certain age groups				
Disability			x	Resources available for those at the end of their life whilst in our services (especially inpatients)
Including those with physical or sensory impairments, those with learning disabilities and those with mental health issues Do you currently monitor who has a disability so that you know how well your service is being used by people with a disability? Are you making reasonable adjustment to meet the needs of the staff, service users, carers and families?				
Gender	x			
This can include male and female or someone who has completed the gender reassignment process from one sex to another Do you have flexible working arrangements for either sex? Is it easier for either men or women to access your proposal?				
Marriage or Civil Partnerships	x			
People who are in a Civil Partnerships must be treated equally to married couples on a wide range of legal matters				

Are the documents and information provided for your service reflecting the appropriate terminology for marriage and civil partnerships?				
Pregnancy or Maternity	x			
This includes women having a baby and women just after they have had a baby Does your service accommodate the needs of expectant and post natal mothers both as staff and service users? Can your service treat staff and patients with dignity and respect relation in to pregnancy and maternity?				
Race or Ethnicity	x			
Including Gypsy or Roma people, Irish people, those of mixed heritage, asylum seekers and refugees What training does staff have to respond to the cultural needs of different ethnic groups? What arrangements are in place to communicate with people who do not have English as a first language?				
Religion or Belief			x	Resources available for those at the end of their life whilst in our services (especially inpatients)
Including humanists and non-believers Is there easy access to a prayer or quiet room to your service delivery area? When organising events – Do you take necessary steps to make sure that spiritual requirements are met?				
Sexual Orientation	x			
Including gay men, lesbians and bisexual people Does your service use visual images that could be people from any background or are the images mainly heterosexual couples? Does staff in your workplace feel comfortable about being ‘out’ or would office culture make them feel this might not be a good idea?				
Transgender or Gender Reassignment	x			
This will include people who are in the process of or in a care pathway changing from one gender to another Have you considered the possible needs of transgender staff and service users in the development of your proposal or service?				
Human Rights			x	Resources available for those at the end of their life whilst in our services especially their right to a dignified death
Affecting someone’s right to Life, Dignity and Respect? Caring for other people or protecting them from danger?				

The detention of an individual inadvertently or placing someone in a humiliating situation or position?				
If a negative or disproportionate impact has been identified in any of the key areas would this difference be illegal / unlawful? I.e. Would it be discriminatory under anti-discrimination legislation. (The Equality Act 2010, Human Rights Act 1998)				
	Yes	**No**		
What do you consider the level of negative impact to be?	**High Impact**	**Medium Impact**	**Low Impact**	**No Impact**
				X
If the impact could be discriminatory in law, please contact the **Equality and Diversity Lead** immediately to determine the next course of action. If the negative impact is high a Full Equality Analysis will be required. If you are unsure how to answer the above questions, or if you have assessed the impact as medium, please seek further guidance from the **Equality and Diversity Lead** before proceeding. If the proposal does not have a negative impact or the impact is considered low, reasonable, or justifiable, then please complete the rest of the form below with any required redial actions, and forward to the **Equality and Diversity Lead.**				
Action Planning:				
How could you minimise or remove any negative impact identified even if this is of low significance?				
How will any impact or planned actions be monitored and reviewed?				
How will you promote equal opportunity and advance equality by sharing good practice to have a positive impact other people as a result of their personal protected characteristic.				
Please save and keep one copy and then send a copy with a copy of the proposal to the Senior Equality and Diversity Lead at bsmhft.hr@nhs.net . The results will then be published on the Trust's website. Please ensure that any resulting actions are incorporated into Divisional or Service planning and monitored on a regular basis				

Appendix 2 - SPICT™



THE UNIVERSITY of EDINBURGH

Supportive and Palliative Care Indicators Tool (SPICT™)

NHS SCOTLAND

The SPICT™ is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.

Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems.
- The person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Look for clinical indicators of one or multiple life-limiting conditions.

Cancer

Functional ability deteriorating due to progressive cancer.

Too frail for cancer treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Urinary and faecal incontinence.

Not able to communicate by speaking; little social interaction.

Frequent falls; fractured femur.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Persistent paralysis after stroke with significant loss of function and ongoing disability.

Heart/ vascular disease

Heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe, chronic lung disease; with breathlessness at rest or on minimal effort between exacerbations.

Persistent hypoxia needing long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Other conditions

Deteriorating and at risk of dying with other conditions or complications that are not reversible; any treatment available will have a poor outcome.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping or not starting dialysis.

Liver disease

Cirrhosis with one or more complications in the past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is not possible.

Review current care and care planning.

- Review current treatment and medication to ensure the person receives optimal care; minimise polypharmacy.
- Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage.
- Agree a current and future care plan with the person and their family. Support family carers.
- Plan ahead early if loss of decision-making capacity is likely.
- Record, communicate and coordinate the care plan.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT™, April 2019

Appendix 3 – Rockwood Clinical Frailty Scale

Rockwood Clinical frailty Scale

Clinical Frailty Scale*

1 **Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

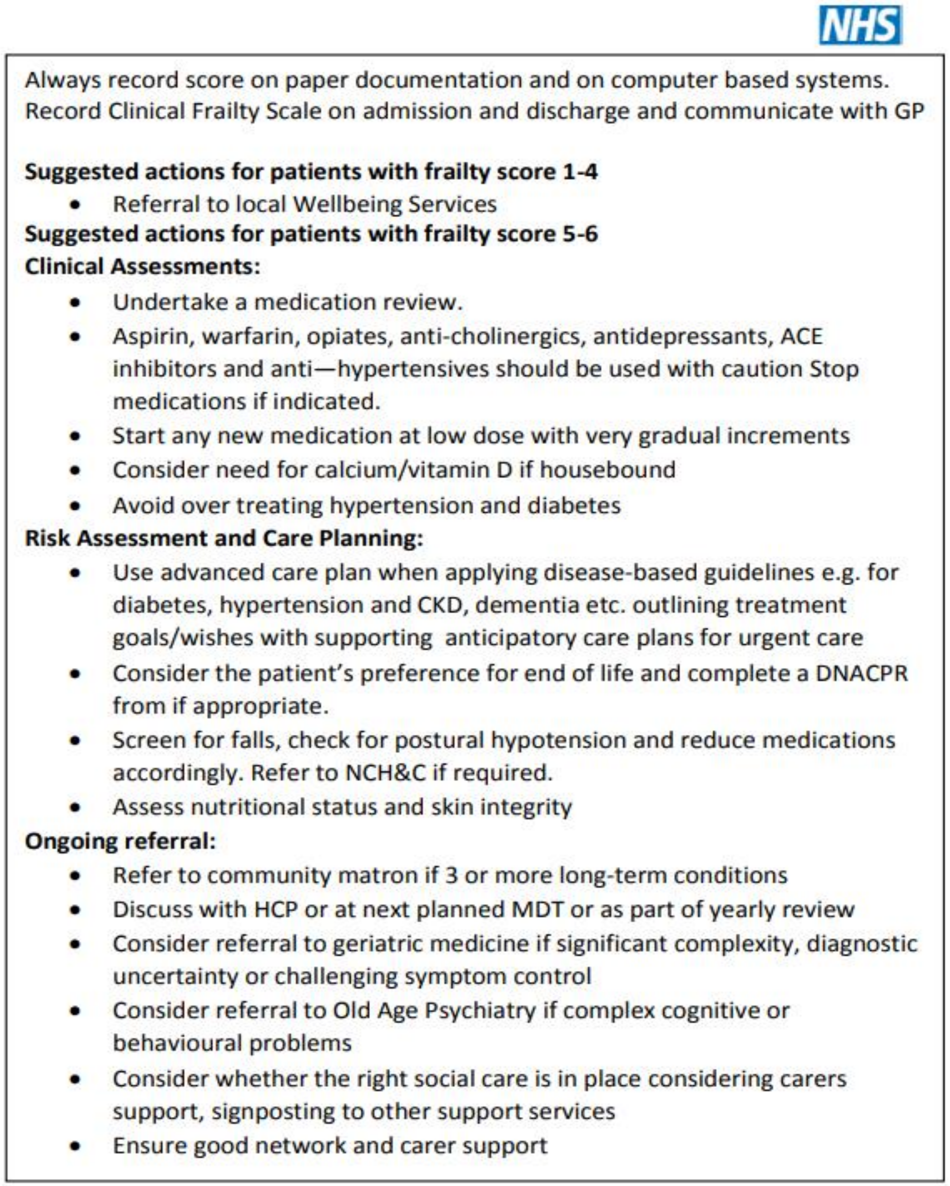
2 **Well** – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.

3 **Managing Well** – People whose **medical problems are well controlled,** but are **not regularly active** beyond routine walking.

4 **Vulnerable** – While **not dependent** on others for daily help, often **symptoms limit activities.** A common complaint is being "slowed up", and/or being tired during the day.

5 **Mildly Frail** – These people often have **more evident slowing,** and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 **Moderately Frail** – People need help with **all outside activities** and with **keeping house.** Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.



Always record score on paper documentation and on computer based systems. Record Clinical Frailty Scale on admission and discharge and communicate with GP

Suggested actions for patients with frailty score 1-4
- Referral to local Wellbeing Services

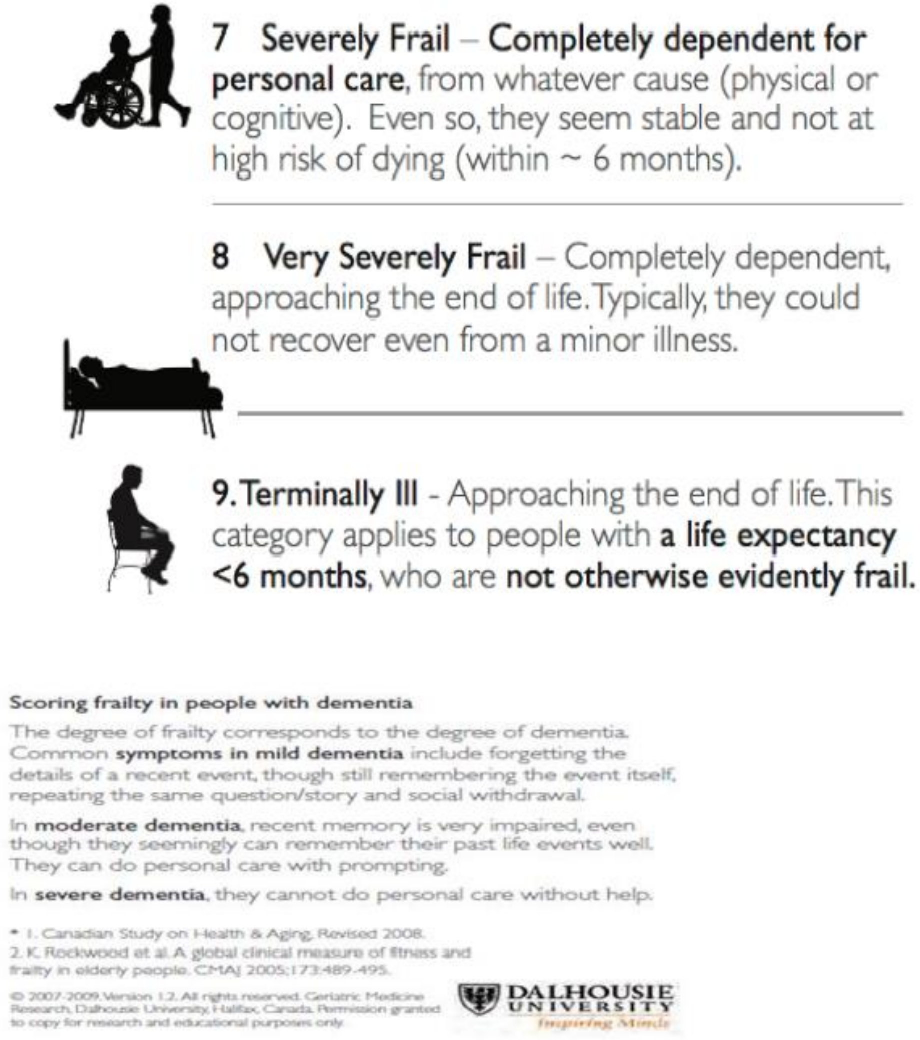
Suggested actions for patients with frailty score 5-6

Clinical Assessments:
- Undertake a medication review.
- Aspirin, warfarin, opiates, anti-cholinergics, antidepressants, ACE inhibitors and anti—hypertensives should be used with caution Stop medications if indicated.
- Start any new medication at low dose with very gradual increments
- Consider need for calcium/vitamin D if housebound
- Avoid over treating hypertension and diabetes

Risk Assessment and Care Planning:
- Use advanced care plan when applying disease-based guidelines e.g. for diabetes, hypertension and CKD, dementia etc. outlining treatment goals/wishes with supporting anticipatory care plans for urgent care
- Consider the patient's preference for end of life and complete a DNACPR from if appropriate.
- Screen for falls, check for postural hypotension and reduce medications accordingly. Refer to NCH&C if required.
- Assess nutritional status and skin integrity

Ongoing referral:
- Refer to community matron if 3 or more long-term conditions
- Discuss with HCP or at next planned MDT or as part of yearly review
- Consider referral to geriatric medicine if significant complexity, diagnostic uncertainty or challenging symptom control
- Consider referral to Old Age Psychiatry if complex cognitive or behavioural problems
- Consider whether the right social care is in place considering carers support, signposting to other support services
- Ensure good network and carer support

Rockwood Clinical frailty Scale



7 Severely Frail – **Completely dependent for personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 Very Severely Frail – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9. Terminally Ill - Approaching the end of life. This category applies to people with **a life expectancy <6 months**, who are **not otherwise evidently frail.**

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

* 1. Canadian Study on Health & Aging, Revised 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

© 2007-2009. Version 1.2. All rights reserved. Geriatric Medicine Research, Dalhousie University, Halifax, Canada. Permission granted to copy for research and educational purposes only.

DALHOUSIE UNIVERSITY *Inspiring Minds*

Suggested actions for patients with frailty score 7-9

Clinical Assessments:

- Undertake a medication review.
- Aspirin, warfarin, opiates, anti-cholinergics, antidepressants, ACE inhibitors and anti—hypertensives should be used with caution Stop medications if indicated.
- Start any new medication at low dose with very gradual increments
- Consider need for calcium/vitamin D if housebound
- Avoid over treating hypertension and diabetes

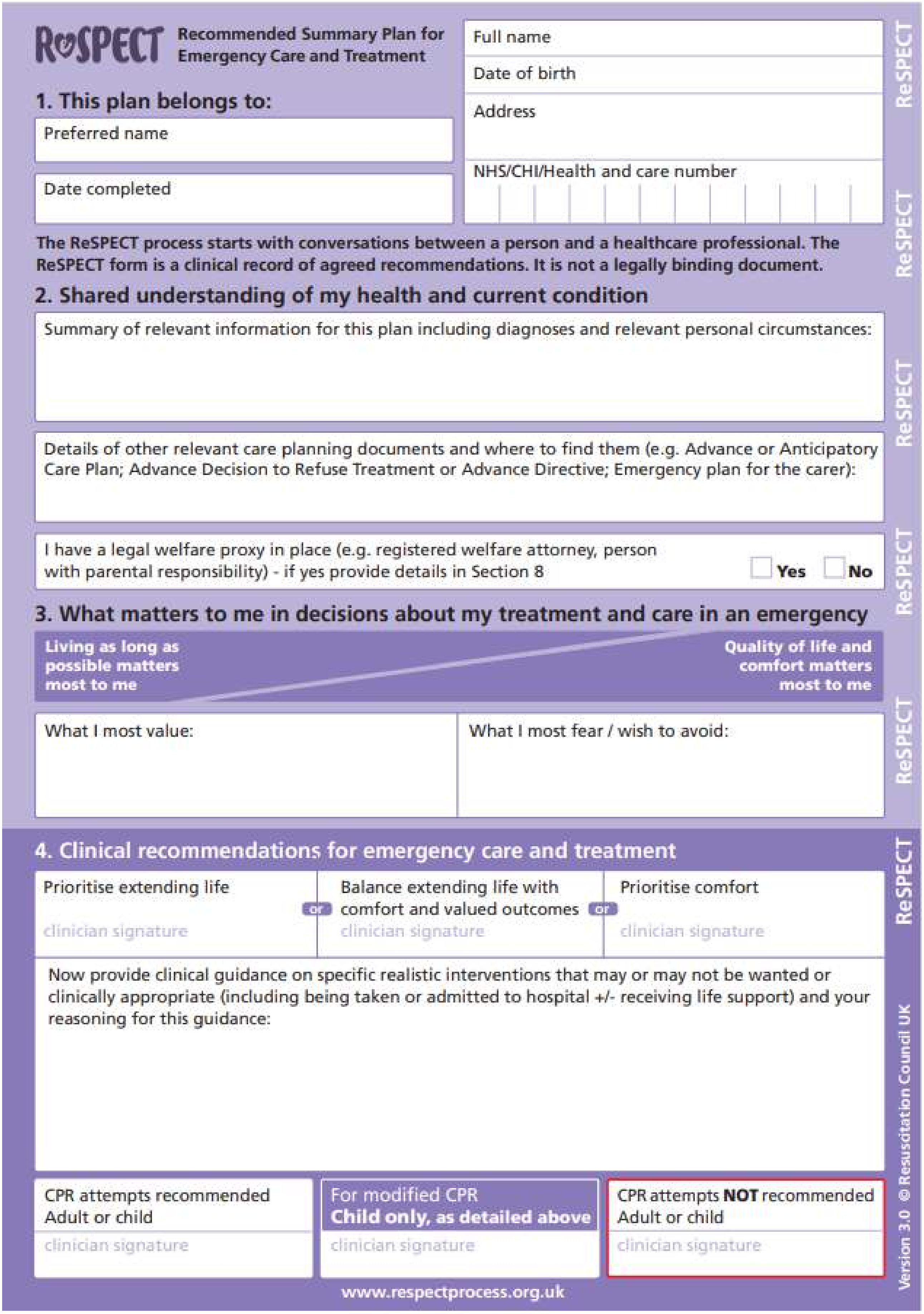
Risk Assessment and Care Planning:

- Use advanced care plan when applying disease-based guidelines e.g. for diabetes, hypertension and CKD, dementia etc. outlining treatment goals/wishes with supporting anticipatory care plans for urgent care
- Discuss the patient's preference for end of life and complete a DNACPR from if appropriate. Anticipatory care plans as part of advanced care planning
- Screen for falls and refer to NCH&C if required
- Check for postural hypotension if falling
- Ask about memory problems and refer on if indicated

Ongoing referral:

- Consider whether the right social care is in place considering carers support, signposting
- Refer to community matron if 3 or more long-term conditions
- Consider referral to geriatric medicine if significant complexity, diagnostic uncertainty or challenging symptom control
- Consider referral to Old Age Psychiatry if complex cognitive or behavioural problems
- Consider entering patient onto the GSF register
- GP practice to deliver a clinical review providing an annual medication review and where clinically appropriate discuss whether the patient has fallen in the last 12 months and provide any other clinically relevant interventions.

Appendix 4 – ReSPECT tool



ReSPECT Recommended Summary Plan for Emergency Care and Treatment

Full name

Date of birth

Address

NHS/CHI/Health and care number

1. This plan belongs to:

Preferred name

Date completed

The ReSPECT process starts with conversations between a person and a healthcare professional. The ReSPECT form is a clinical record of agreed recommendations. It is not a legally binding document.

2. Shared understanding of my health and current condition

Summary of relevant information for this plan including diagnoses and relevant personal circumstances:

Details of other relevant care planning documents and where to find them (e.g. Advance or Anticipatory Care Plan; Advance Decision to Refuse Treatment or Advance Directive; Emergency plan for the carer):

I have a legal welfare proxy in place (e.g. registered welfare attorney, person with parental responsibility) - if yes provide details in Section 8 ☐ **Yes** ☐ **No**

3. What matters to me in decisions about my treatment and care in an emergency

Living as long as possible matters most to me

Quality of life and comfort matters most to me

What I most value:

What I most fear / wish to avoid:

4. Clinical recommendations for emergency care and treatment

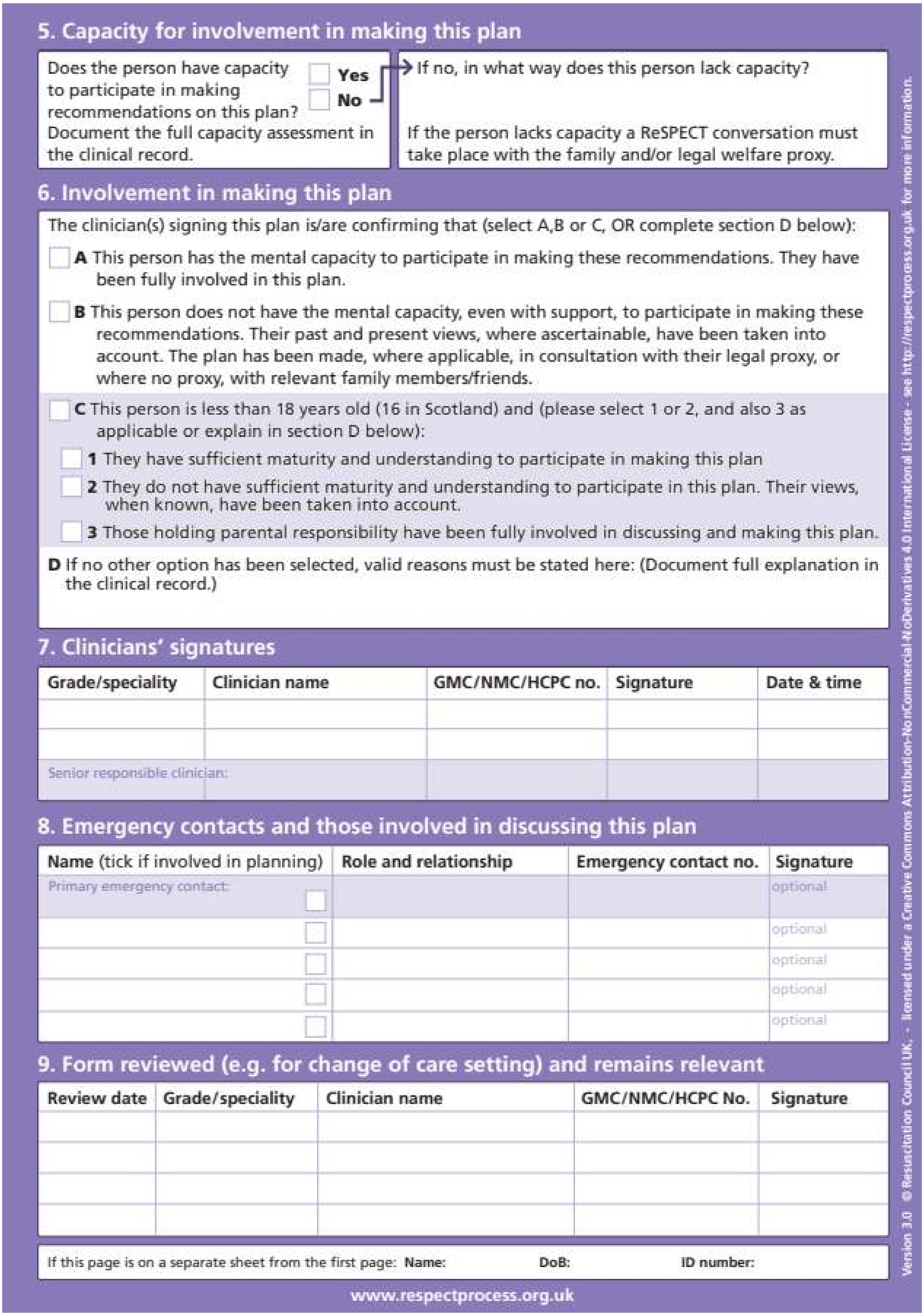
Prioritise extending life clinician signature	or	Balance extending life with comfort and valued outcomes clinician signature	or	Prioritise comfort clinician signature

Now provide clinical guidance on specific realistic interventions that may or may not be wanted or clinically appropriate (including being taken or admitted to hospital +/- receiving life support) and your reasoning for this guidance:

CPR attempts recommended Adult or child	For modified CPR **Child only, as detailed above**	CPR attempts **NOT** recommended Adult or child
clinician signature	clinician signature	clinician signature

www.respectprocess.org.uk

Version 3.0 © Resuscitation Council UK



5. Capacity for involvement in making this plan

Does the person have capacity to participate in making recommendations on this plan? ☐ **Yes** ☐ **No**
Document the full capacity assessment in the clinical record.

→ If no, in what way does this person lack capacity?

If the person lacks capacity a ReSPECT conversation must take place with the family and/or legal welfare proxy.

6. Involvement in making this plan

The clinician(s) signing this plan is/are confirming that (select A,B or C, OR complete section D below):

☐ **A** This person has the mental capacity to participate in making these recommendations. They have been fully involved in this plan.

☐ **B** This person does not have the mental capacity, even with support, to participate in making these recommendations. Their past and present views, where ascertainable, have been taken into account. The plan has been made, where applicable, in consultation with their legal proxy, or where no proxy, with relevant family members/friends.

☐ **C** This person is less than 18 years old (16 in Scotland) and (please select 1 or 2, and also 3 as applicable or explain in section D below):

- ☐ **1** They have sufficient maturity and understanding to participate in making this plan
- ☐ **2** They do not have sufficient maturity and understanding to participate in this plan. Their views, when known, have been taken into account.
- ☐ **3** Those holding parental responsibility have been fully involved in discussing and making this plan.

D If no other option has been selected, valid reasons must be stated here: (Document full explanation in the clinical record.)

7. Clinicians' signatures

Grade/speciality	Clinician name	GMC/NMC/HCPC no.	Signature	Date & time
Senior responsible clinician:				

8. Emergency contacts and those involved in discussing this plan

Name (tick if involved in planning)	Role and relationship	Emergency contact no.	Signature
Primary emergency contact: ☐			optional
☐			optional
☐			optional
☐			optional
☐			optional

9. Form reviewed (e.g. for change of care setting) and remains relevant

Review date	Grade/speciality	Clinician name	GMC/NMC/HCPC No.	Signature

If this page is on a separate sheet from the first page: **Name:** **DoB:** **ID number:**

www.respectprocess.org.uk

The ReSPECT conversation and completion of the form is only to be done by medical staff (FY2 and higher) and nursing staff (ANP level) who have undertaken appropriate recognised RCUK ReSPECT training).
They must be able to understand and answer the psychological and physiological questions. The form must then be endorsed by the clinician responsible for the person's care, i.e., their consultant, GP, or appropriate deputy within 7 days.

Appendix 5 – ReSPECT treatment escalation Protocol

This form is designed as guidance to clinicians on the types of interventions which may or may not be suitable or appropriate for patients who are physically unwell. It should be completed by senior clinicians but involve the MDT.

Does the patient have capacity to decide on their physical treatment?

Impairment of mind/brain:	Yes/No
Able to understand:	Yes/No
Able to retain:	Yes/No
Able to weigh up:	Yes/No
Able to communicate:	Yes/No

Reasons for above decision:

Does the patient have an advanced directive?	Yes/No
Does the patient have a representative? (IMCA/NoK/Court of Protection): (If yes provide details)	Yes/No

Interventions

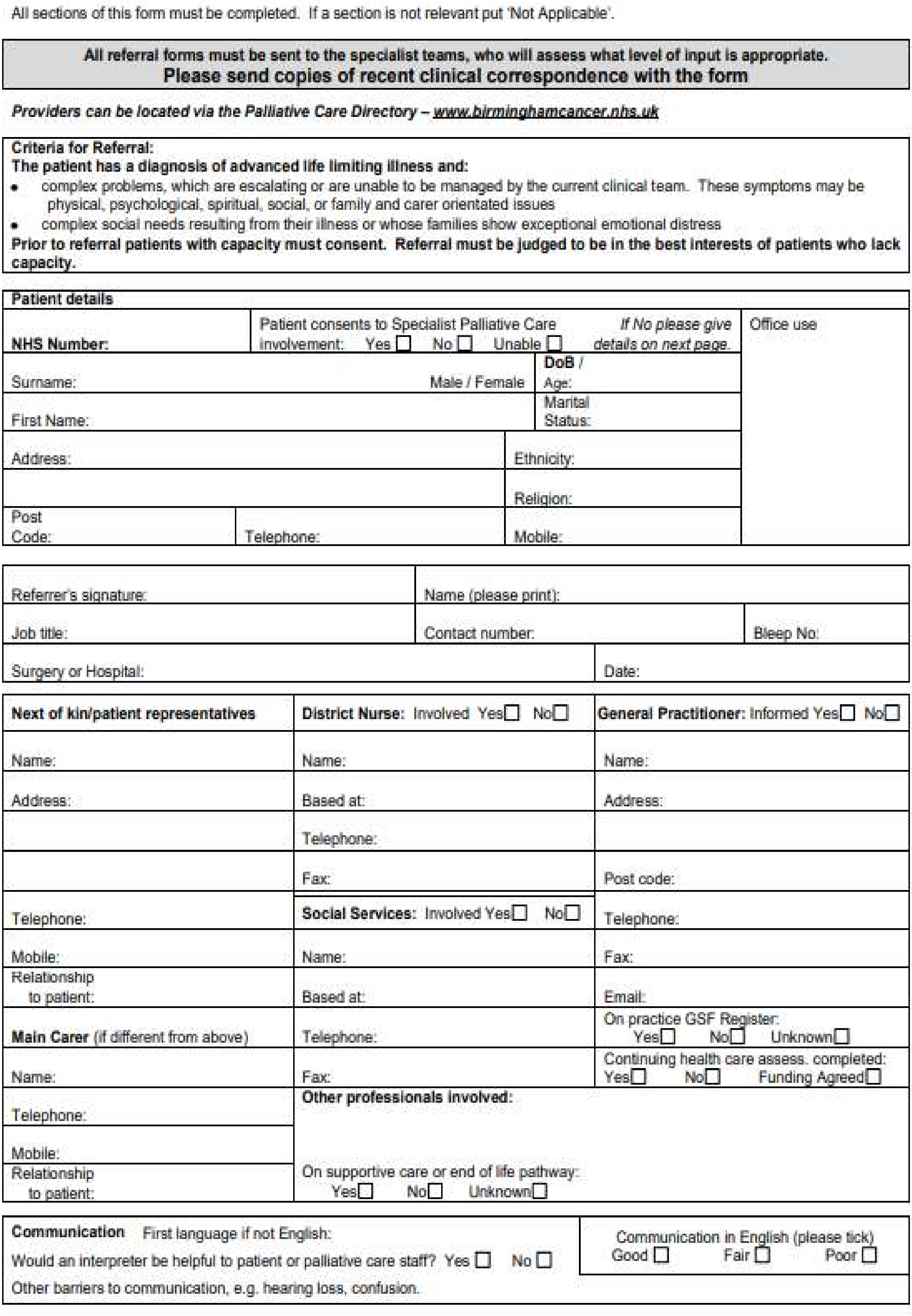
Is CPR appropriate? (If not please review there is a ReSPECT plan in place)	Yes/No
Is a 9999-call appropriate?	Yes/No
Is critical care (ITU) intervention appropriate?	Yes/No
Is referral to acute hospital appropriate?	Yes/No
Is artificial feeding appropriate?	Yes/No
Are IV fluids appropriate?	Yes/No
Are antibiotics appropriate?	Yes/No

Other treatments to be withheld:

Who has this been discussed with: (family, representatives)

Persons making decision: (senior clinician name and grade and names/grades of MDT)

Appendix 6 – Adult Specialist Palliative Care Referral Form – Version 3



All sections of this form must be completed. If a section is not relevant put 'Not Applicable'.

All referral forms must be sent to the specialist teams, who will assess what level of input is appropriate.
Please send copies of recent clinical correspondence with the form

Providers can be located via the Palliative Care Directory – www.birminghamcancer.nhs.uk

Criteria for Referral:
The patient has a diagnosis of advanced life limiting illness and:

- complex problems, which are escalating or are unable to be managed by the current clinical team. These symptoms may be physical, psychological, spiritual, social, or family and carer orientated issues
- complex social needs resulting from their illness or whose families show exceptional emotional distress

Prior to referral patients with capacity must consent. Referral must be judged to be in the best interests of patients who lack capacity.

Patient details

NHS Number:	Patient consents to Specialist Palliative Care involvement: Yes ☐ No ☐ Unable ☐	*If No please give details on next page.*	Office use
Surname: Male / Female		**DoB /** Age:	
First Name:		Marital Status:	
Address:		Ethnicity:	
		Religion:	
Post Code:	Telephone:	Mobile:	

Referrer's signature:	Name (please print):	
Job title:	Contact number:	Bleep No:
Surgery or Hospital:	Date:	

Next of kin/patient representatives	**District Nurse:** Involved Yes☐ No☐	**General Practitioner:** Informed Yes☐ No☐
Name:	Name:	Name:
Address:	Based at:	Address:
	Telephone:	
	Fax:	Post code:
Telephone:	**Social Services:** Involved Yes☐ No☐	Telephone:
Mobile:	Name:	Fax:
Relationship to patient:	Based at:	Email:
Main Carer (if different from above)	Telephone:	On practice GSF Register: Yes☐ No☐ Unknown☐
Name:	Fax:	Continuing health care assess. completed: Yes☐ No☐ Funding Agreed☐
Telephone:	**Other professionals involved:**	
Mobile:		
Relationship to patient:	On supportive care or end of life pathway: Yes☐ No☐ Unknown☐	

Communication First language if not English:

Would an interpreter be helpful to patient or palliative care staff? Yes ☐ No ☐

Other barriers to communication, e.g. hearing loss, confusion.

Communication in English (please tick)
Good ☐ Fair ☐ Poor ☐

Inpatient details (if appropriate)		
Hospital:	Ward:	Hospital Number:
Telephone:	Direct Ward Ext:	Date of discharge (if known):
Consultant (1):		Consultant (2):
Hospital Palliative Care team involved: Yes ☐ No ☐ Key Team CNS/Contact:	MRSA Status: Positive ☐ Negative ☐ Unknown ☐	C Diff. Status: Positive ☐ Negative ☐ Unknown ☐

Main Diagnosis(es):	
Other Significant Medical & Mental Health Problems:	

Brief history of diagnosis(es) and key treatments		
Date	Progression of disease and investigations/treatment	Consultant and hospital

Referrer's expectation of current treatment if relevant: Symptom control ☐ Life prolonging ☐ Curative ☐

Estimated prognosis: Days ☐ Weeks ☐ Months ☐ Years ☐

Service Required ☐Home assessment and support ☐Day Hospice ☐Admission - *please circle reason below* symptom control / terminal care / respite care *(respite is often pre-booked & limited to patients with SPC needs)*	**The patient is currently** ☐At home ☐In hospital ☐Elsewhere (e.g. NH, with family) .... Does the patient live alone? Yes ☐ No ☐ Add details below
Preferred place of care:	Preferred place of death if different:

Indicators for Referral ☐Pain / symptom control ☐Patient Emotional / psychosocial / spiritual support ☐Carer support
☐Other reason. e.g. lymphoedema. Please detail....

Please outline the **issues** & specify what **treatments or strategies** have already been tried:

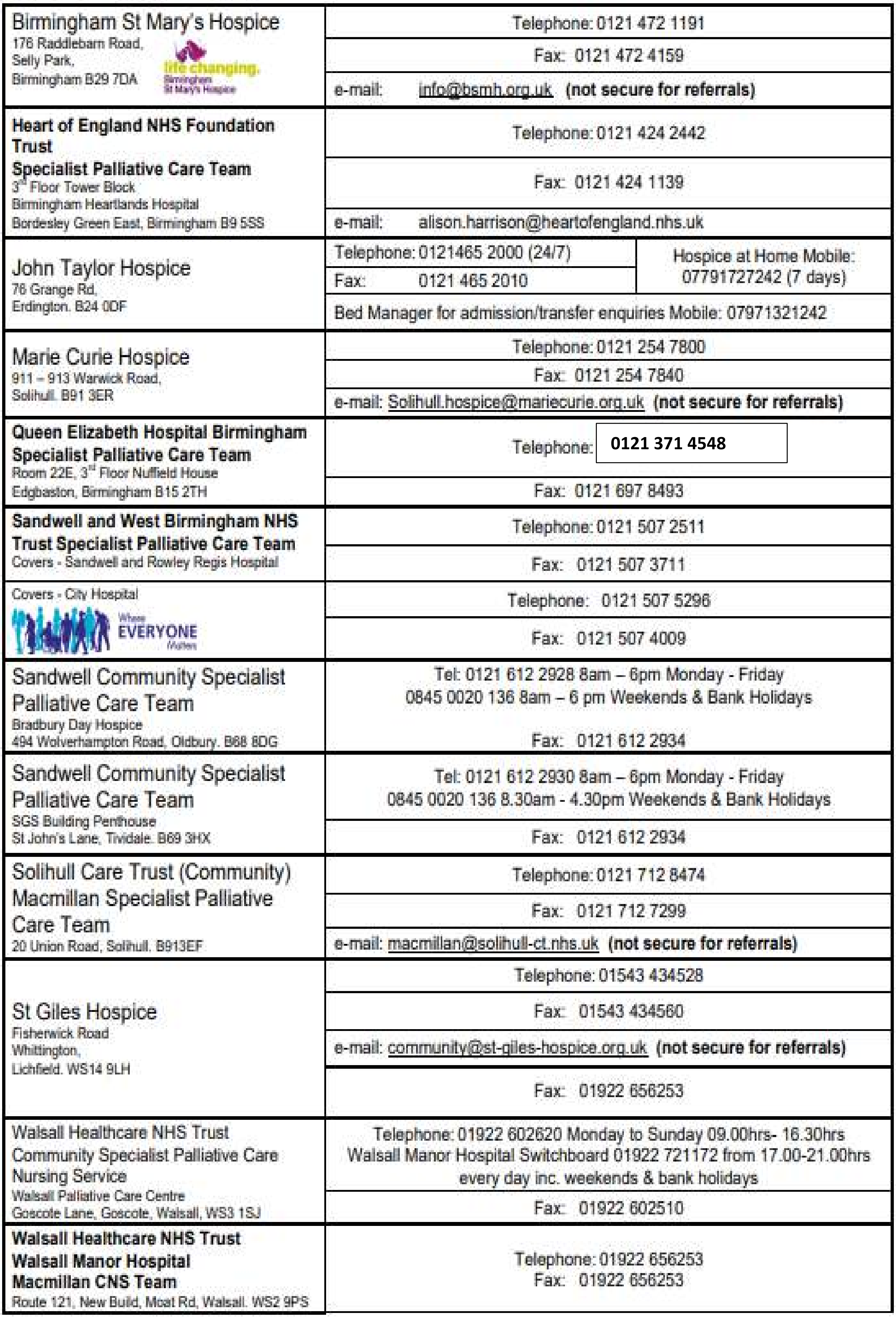
Urgency of referral:	**Within 1 day** ☐ - **MUST** be accompanied by a telephone call from the referrer for immediate advice
	Within 5 working days ☐ **Within 10 working days** ☐ **1st contact by SPC team may be by phone.** ☐

Allergies/ sensitivities	**MEDICATION (ATTACH a list of current & recent prescriptions)**

Insight	Has patient been told diagnosis?	Yes ☐	No ☐	Is the carer aware of patient's prognosis?	Yes ☐	No ☐
	Is patient aware of prognosis?	Yes ☐	No ☐	Is the carer aware of patient's referral?	Yes ☐	No ☐
	Does patient discuss the illness freely?	Yes ☐	No ☐	*Please provide details in **Issues** section if any "No" responses*		

Please ensure patients are aware information will be held on computer according to the Data Protection Act

Appendix 7 – Contact Details for Adult Specialist Palliative Care Service



Birmingham St Mary's Hospice 176 Raddlebarn Road, Selly Park, Birmingham B29 7DA	Telephone: 0121 472 1191 Fax: 0121 472 4159 e-mail: info@bsmh.org.uk **(not secure for referrals)**
Heart of England NHS Foundation Trust **Specialist Palliative Care Team** 3rd Floor Tower Block Birmingham Heartlands Hospital Bordesley Green East, Birmingham B9 5SS	Telephone: 0121 424 2442 Fax: 0121 424 1139 e-mail: alison.harrison@heartofengland.nhs.uk
John Taylor Hospice 76 Grange Rd, Erdington. B24 0DF	Telephone: 0121465 2000 (24/7) Fax: 0121 465 2010 Hospice at Home Mobile: 07791727242 (7 days) Bed Manager for admission/transfer enquiries Mobile: 07971321242
Marie Curie Hospice 911 – 913 Warwick Road, Solihull. B91 3ER	Telephone: 0121 254 7800 Fax: 0121 254 7840 e-mail: Solihull.hospice@mariecurie.org.uk **(not secure for referrals)**
Queen Elizabeth Hospital Birmingham **Specialist Palliative Care Team** Room 22E, 3rd Floor Nuffield House Edgbaston, Birmingham B15 2TH	Telephone: **0121 371 4548** Fax: 0121 697 8493
Sandwell and West Birmingham NHS Trust Specialist Palliative Care Team Covers - Sandwell and Rowley Regis Hospital	Telephone: 0121 507 2511 Fax: 0121 507 3711
Covers - City Hospital Where EVERYONE Matters	Telephone: 0121 507 5296 Fax: 0121 507 4009
Sandwell Community Specialist Palliative Care Team Bradbury Day Hospice 494 Wolverhampton Road, Oldbury. B68 8DG	Tel: 0121 612 2928 8am – 6pm Monday - Friday 0845 0020 136 8am – 6 pm Weekends & Bank Holidays Fax: 0121 612 2934
Sandwell Community Specialist Palliative Care Team SGS Building Penthouse St John's Lane, Tividale. B69 3HX	Tel: 0121 612 2930 8am – 6pm Monday - Friday 0845 0020 136 8.30am - 4.30pm Weekends & Bank Holidays Fax: 0121 612 2934
Solihull Care Trust (Community) Macmillan Specialist Palliative Care Team 20 Union Road, Solihull. B913EF	Telephone: 0121 712 8474 Fax: 0121 712 7299 e-mail: macmillan@solihull-ct.nhs.uk **(not secure for referrals)**
St Giles Hospice Fisherwick Road Whittington, Lichfield. WS14 9LH	Telephone: 01543 434528 Fax: 01543 434560 e-mail: community@st-giles-hospice.org.uk **(not secure for referrals)** Fax: 01922 656253
Walsall Healthcare NHS Trust Community Specialist Palliative Care Nursing Service Walsall Palliative Care Centre Goscote Lane, Goscote, Walsall, WS3 1SJ	Telephone: 01922 602620 Monday to Sunday 09.00hrs- 16.30hrs Walsall Manor Hospital Switchboard 01922 721172 from 17.00-21.00hrs every day inc. weekends & bank holidays Fax: 01922 602510
Walsall Healthcare NHS Trust **Walsall Manor Hospital** **Macmillan CNS Team** Route 121, New Build, Moat Rd, Walsall. WS2 9PS	Telephone: 01922 656253 Fax: 01922 656253

Appendix 8 - Anticipatory Medication Guidelines

Symptoms commonly experienced by patients entering the terminal phase include pain, agitation, nausea, vomiting, breathlessness, and excessive chest secretions.

To provide prompt and effective symptom control and to reduce distress and anxiety for patients and their carers, it is advocated that medications used to manage these symptoms are prescribed in anticipation of need. These medications are prescribed in anticipation of patient being unable to swallow their regular symptom control medications and given by the subcutaneous (SC) route if needed when unable to take by oral route.

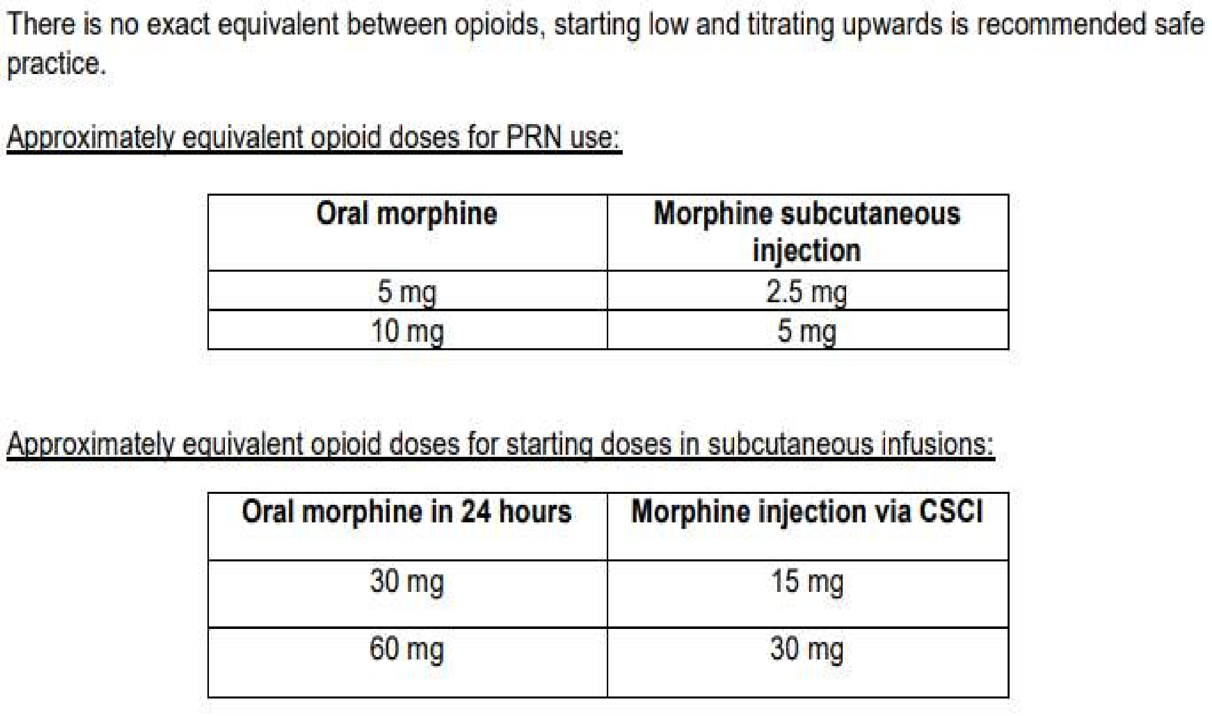
The following table and algorithms outline examples of common doses of drugs used to treat the above symptoms and is for use in all settings. They have been designed to be used in conjunction with any local prescribing guidance and authorisation forms.

For further information or if symptoms not managed, please contact the local palliative care team or pharmacist for specialist advise in Apprendix 7

For the purposes of this document the dying phase is considered to be a prognosis of less than six weeks, or if 'phase of illness' ranking is used then when patient considered to be 'deteriorating' or 'dying' Recognising the Dying Phase – West Midlands Palliative Care (westmidspallcare.co.uk)).

Symptom	Drug	Dose	Route	Notes
Pain (eGFR >30)	Morphine Sulfate If eGFR <30 consider either opioid switch below, or dose reduction	2.5 - 5mg	Subcutaneous injection	If patient already taking regular morphine the PRN dose is usually 1/6th of the 24 hour opioid dose. For patients receiving alternative opioids please contact the palliative care team or pharmacist for advice.
Pain (eGFR<30)	See specialist algorithm for either Fentanyl or Alfentanil			
Agitation	Midazolam	2.5mg - 5mg *(If eGFR <30 dose reduction to 1.25mg – 2.5mg)	Subcutaneous injection	To be given hourly as required. Maximum 60mg in 24hrs. N.B. if eGFR <30 Maximum 30mg in 24hrs
Nausea and vomiting	Levomepromazine	2.5mg - 5mg	Subcutaneous injection	Four hourly as required. Maximum dose 25mg in 24 hours
Chest Secretions	Hyoscine butylbromide	20mg	Subcutaneous injection	Two hourly as required. Maximum dose 180mg in 24 hours
Breathlessness	Morphine Sulphate	2.5-5mg -2.5mg *(If eGFR <30 dose reduction to 1.25mg – 2.5mg)	Subcutaneous injection	Hourly as required

Appendix 9 - OPIOID CONVERSATION: Anticipatory medication



There is no exact equivalent between opioids, starting low and titrating upwards is recommended safe practice.

Approximately equivalent opioid doses for PRN use:

Oral morphine	Morphine subcutaneous injection
5 mg	2.5 mg
10 mg	5 mg

Approximately equivalent opioid doses for starting doses in subcutaneous infusions:

Oral morphine in 24 hours	Morphine injection via CSCI
30 mg	15 mg
60 mg	30 mg

Opioid choice in pre–existing renal impairment: Morphine is NOT routinely use as a continuous infusion in patients with known renal impairment (<30) because of the high risk of accumulation and adverse effects.

However it is **not** necessary to routinely check the renal function of all dying patients who are comfortable on their regular opioid - even if they develop undetected renal impairment, it may not be necessary to convert to an alternative unless they develop side effects or signs of opioid toxicity such as myoclonic jerks; please note drowsiness and reduced consciousness can be part of the dying process and doesn't necessarily mean the person is opioid toxic. If eGFR <30 see our specialist algorithm for either Fentanyl Using-FENTANYL-for-analgesia-in-renal-failure.pdf (westmidspallcare.co.uk) or Alfentanil Prescribing-Algorithm-for-Pain-for-patients-with-renal-impairment-using-ALFENTANIL-injection-subcutaneously-FINAL.pdf (westmidspallcare.co.uk), the choice of drug will be locality specific.

Seek Specialist Palliative Care Advice: If converting from alternative strong opioids, if analgesia requirements are escalating, distressing opioid side effects, if clinician is unclear about appropriate choice of opioid or an alternative opioid is prescribed.

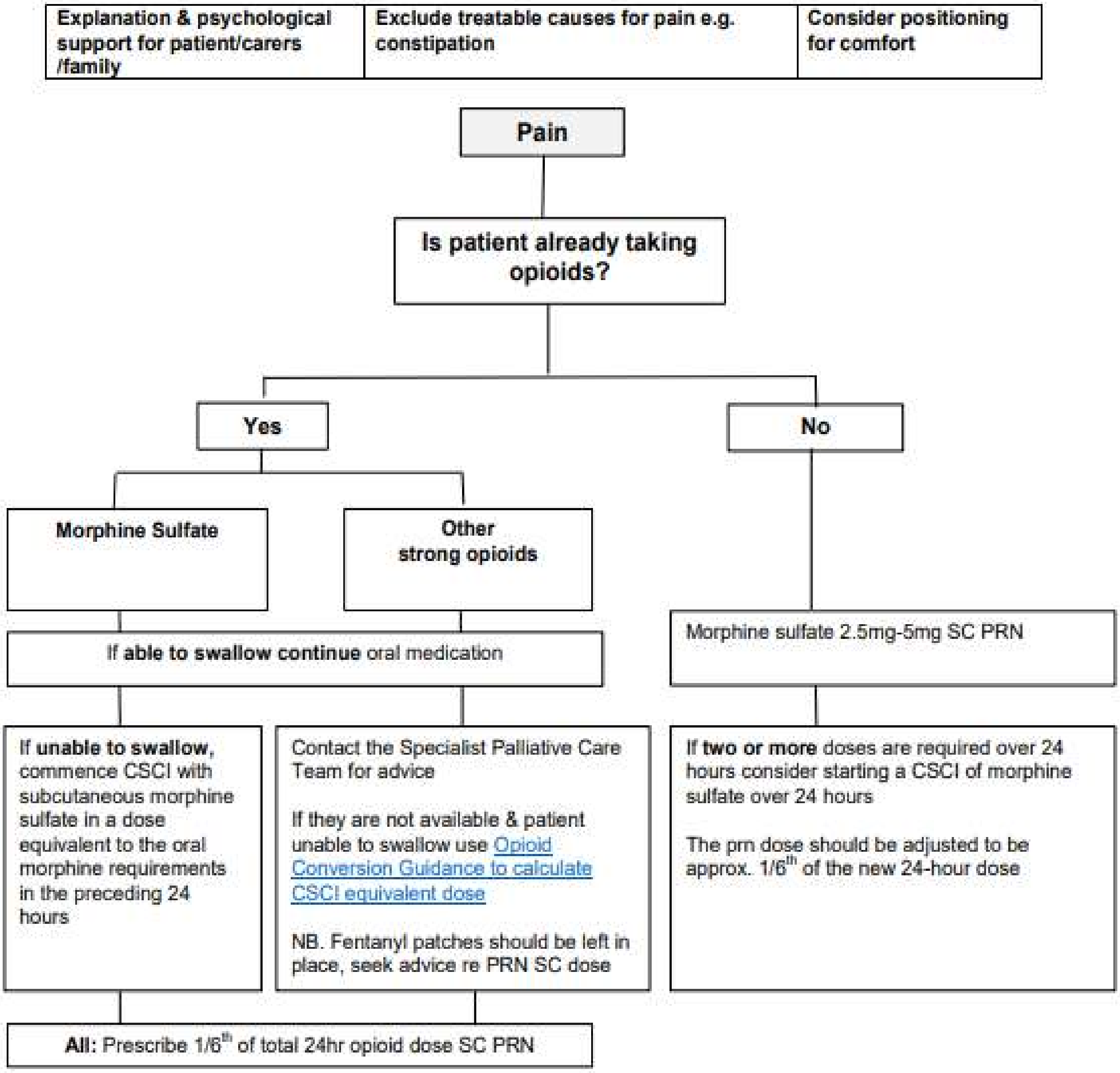
Further information

wmpcp – West Midlands Palliative Care (westmidspallcare.co.uk)

Appendix 10 - Pain

ANTICIPATORY-medication-guideline.pdf (westmidspallcare.co.uk)

Algorithm for Pain in patients using Morphine Sulfate SUBCUTANEOUSLY (eGFR > 30mL/min)



Explanation & psychological support for patient/carers /family

Exclude treatable causes for pain e.g. constipation

Consider positioning for comfort

Pain

Is patient already taking opioids?

Yes

No

Morphine Sulfate

Other strong opioids

If **able to swallow continue** oral medication

Morphine sulfate 2.5mg-5mg SC PRN

If **unable to swallow**, commence CSCI with subcutaneous morphine sulfate in a dose equivalent to the oral morphine requirements in the preceding 24 hours

Contact the Specialist Palliative Care Team for advice

If they are not available & patient unable to swallow use Opioid Conversion Guidance to calculate CSCI equivalent dose

NB. Fentanyl patches should be left in place, seek advice re PRN SC dose

If **two or more** doses are required over 24 hours consider starting a CSCI of morphine sulfate over 24 hours

The prn dose should be adjusted to be approx. 1/6th of the new 24-hour dose

All: Prescribe 1/6th of total 24hr opioid dose SC PRN

Example conversions:

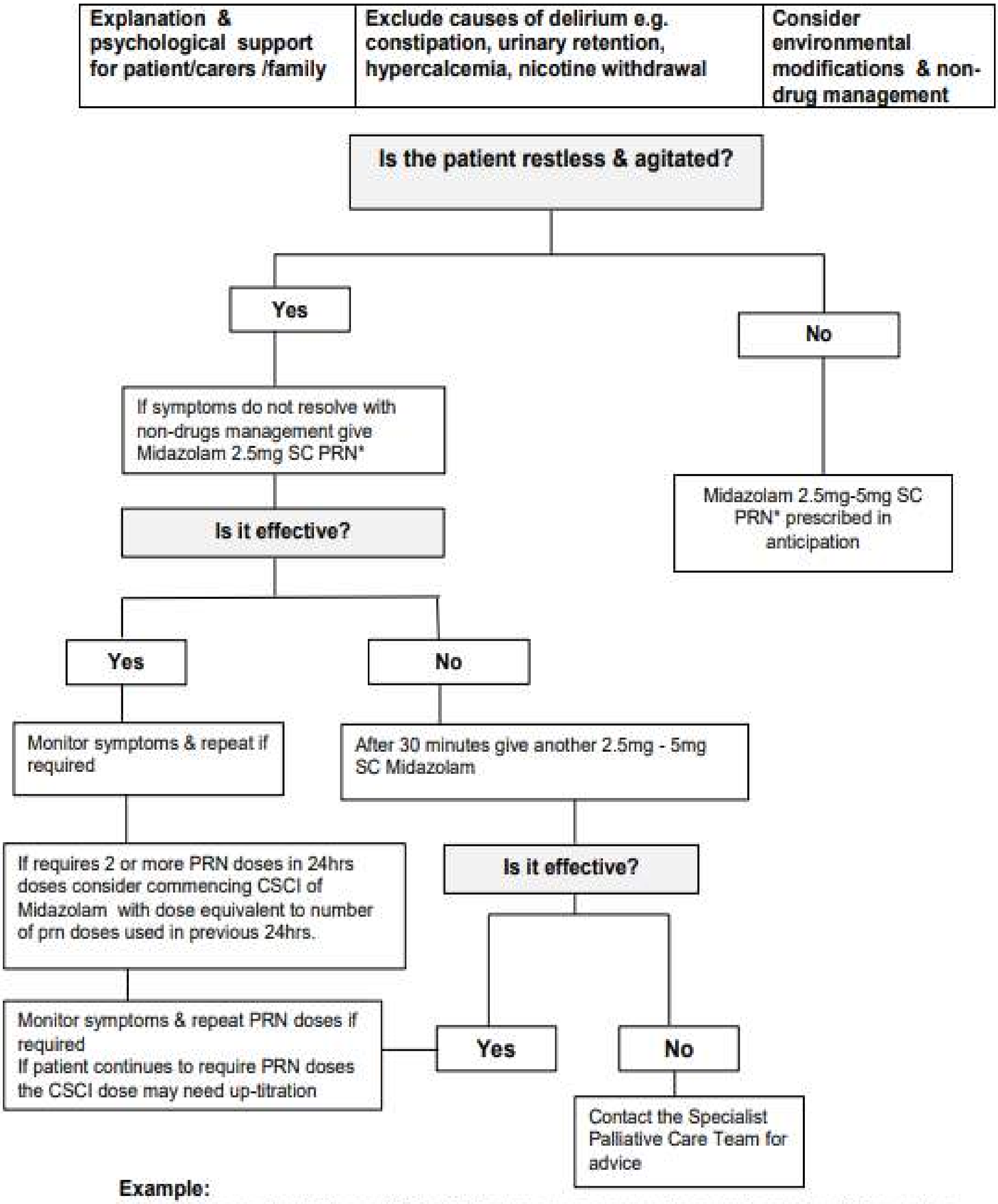
1. To calculate the equivalent total 24 hourly dose of SC morphine, divide total 24 hourly dose of regular oral morphine plus sum total of Oramorph PRNs used by 2 (e.g. 20mg oral morphine = 10mg SC morphine)
2. To calculate the breakthrough dose of morphine sulphate divide total 24-hourly dose of SC morphine by 6 and prescribe this dose, 2 hourly SC PRN (e.g. 15mg SC morphine over 24 hours = 15mg/6 = 2.5mg SC PRN)

Review pain at each assessment - if more than 2 PRN doses used in 24hrs, consider if 24hr CSCI needs to be increased or seek specialist advice.

Appendix 11 - Agitation

[ANTICIPATORY-medication-guideline.pdf (westmidspallcare.co.uk)](ANTICIPATORY-medication-guideline.pdf)

Algorithm for Agitation



Example:

If patient has required 4 doses of 2.5mg Midazolam to manage restlessness in previous 24 hours then a suitable dose would be 10mg midazolam in CSCI over 24hours.

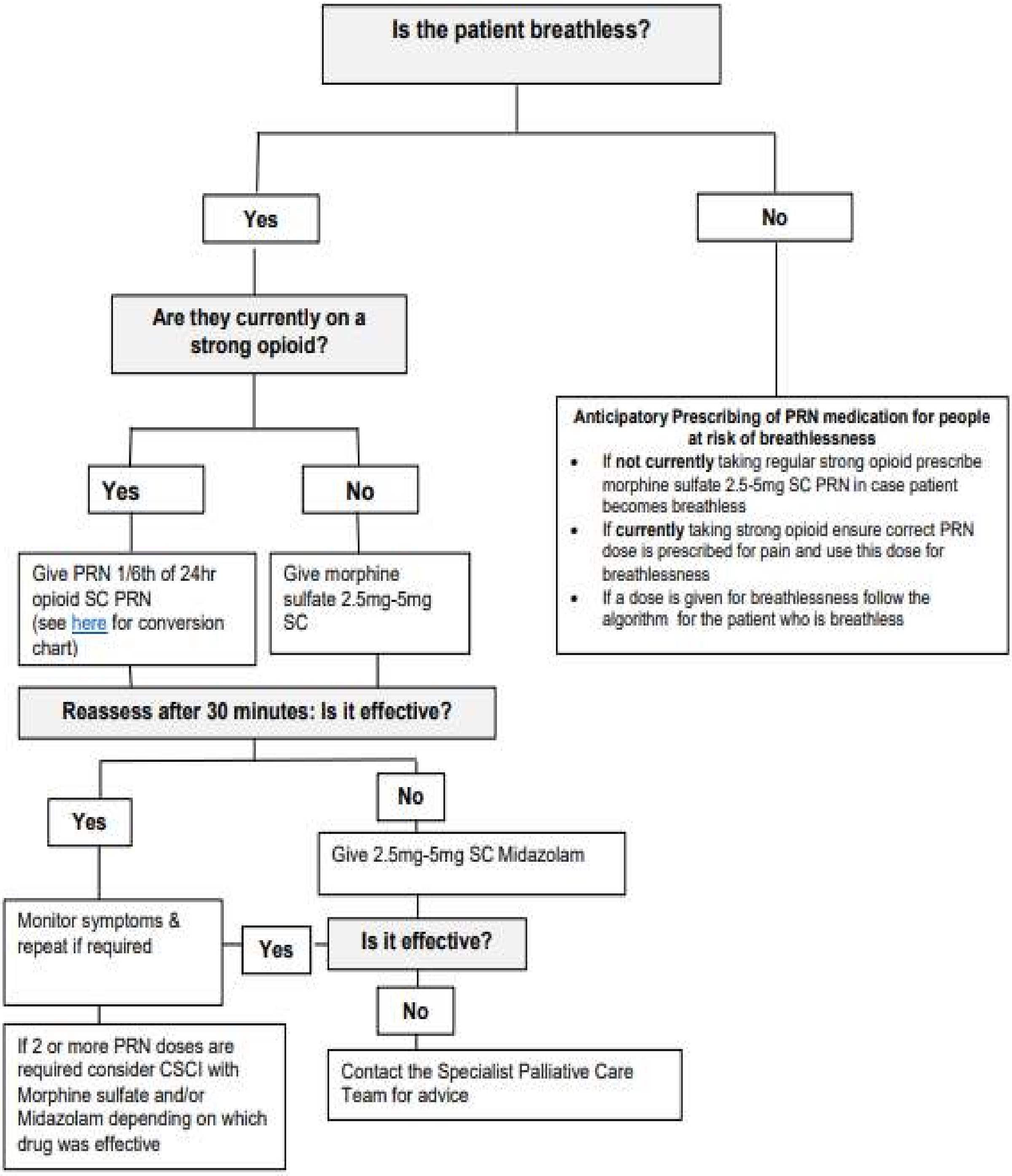
*If eGFR <30 dose give reduced dose of Midazolam 1.25mg – 2.5mg

Appendix 12 - Breathlessness

[ANTICIPATORY-medication-guideline.pdf (westmidspallcare.co.uk)](#)

Algorithm for Breathlessness

Explanation & psychological support for patient/carers /family	**Consider causes** **pleural effusion, heart failure pneumonia & treat if appropriate** **Check blood oxygen levels consider if oxygen appropriate**	**Non pharmacological approaches e.g. positioning, reduce room temperature ,cooling the face by using a cool flannel or cloth**



Is the patient breathless?

Are they currently on a strong opioid?

Give PRN 1/6th of 24hr opioid SC PRN (see [here](#) for conversion chart)

Give morphine sulfate 2.5mg-5mg SC

Reassess after 30 minutes: Is it effective?

Give 2.5mg-5mg SC Midazolam

Is it effective?

Monitor symptoms & repeat if required

If 2 or more PRN doses are required consider CSCI with Morphine sulfate and/or Midazolam depending on which drug was effective

Contact the Specialist Palliative Care Team for advice

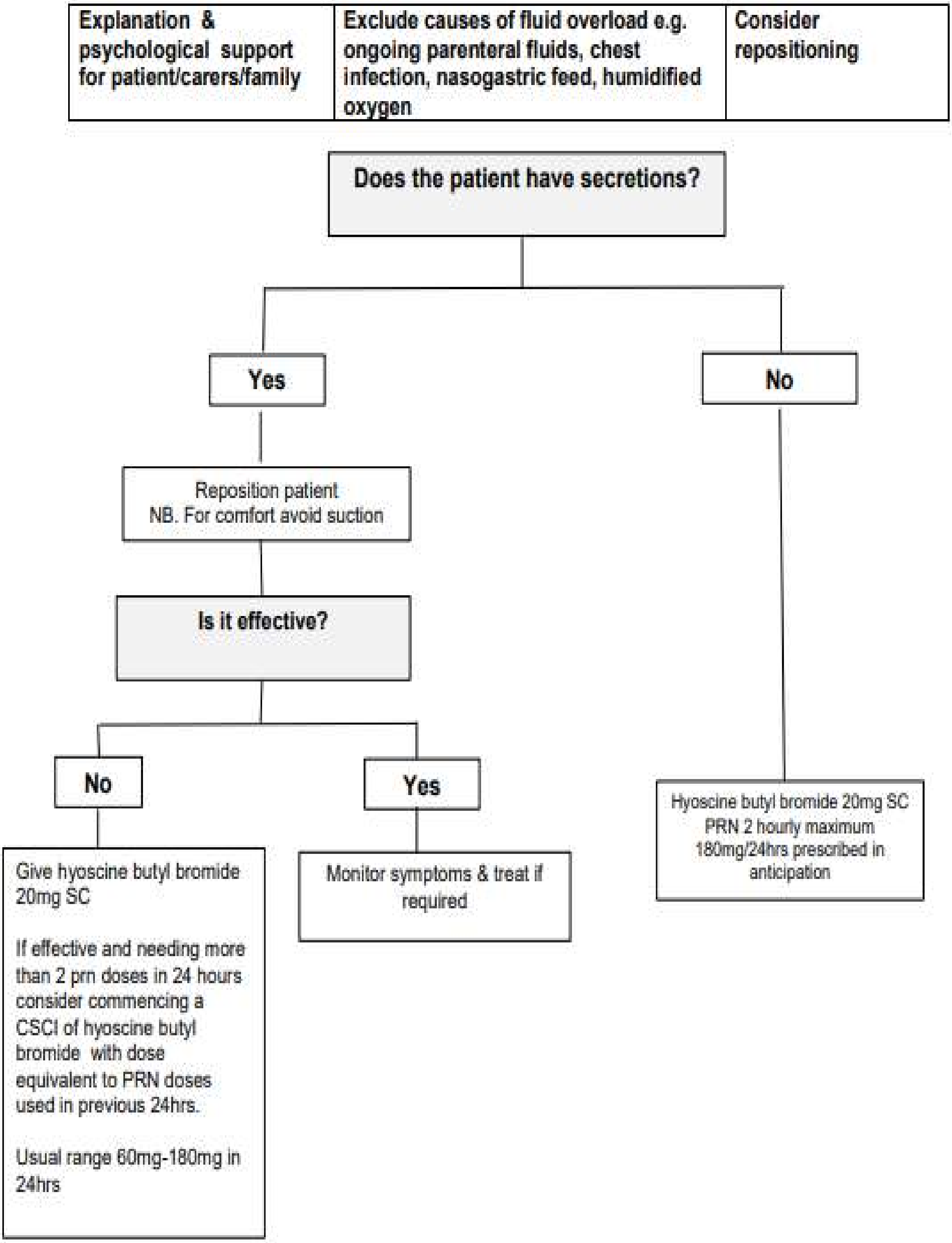
Anticipatory Prescribing of PRN medication for people at risk of breathlessness

- If **not currently** taking regular strong opioid prescribe morphine sulfate 2.5-5mg SC PRN in case patient becomes breathless
- If **currently** taking strong opioid ensure correct PRN dose is prescribed for pain and use this dose for breathlessness
- If a dose is given for breathlessness follow the algorithm for the patient who is breathless

Appendix 13 – Respiratory Secretions

ANTICIPATORY-medication-guideline.pdf (westmidspallcare.co.uk)

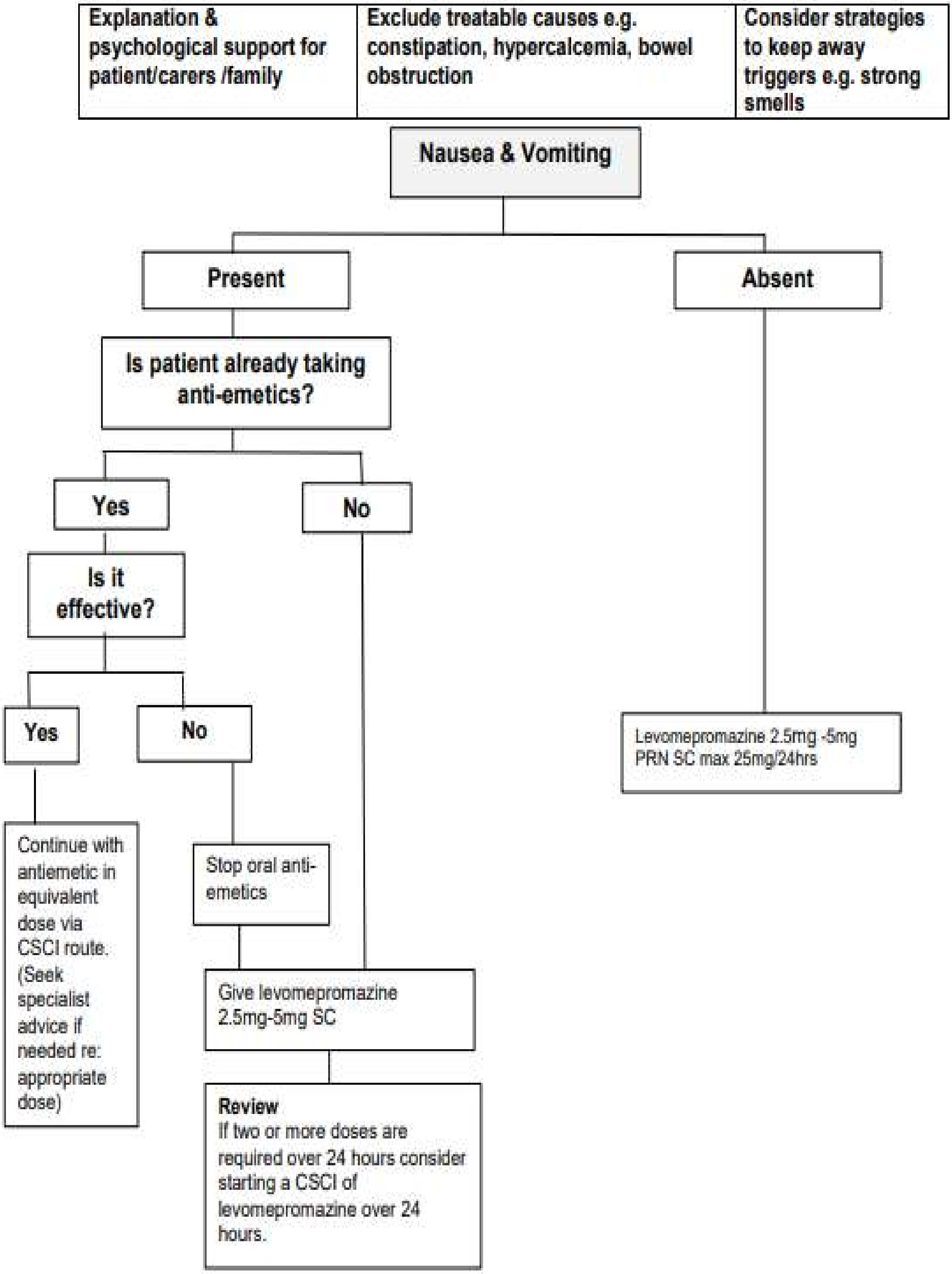
Algorithm for Respiratory Secretions



Appendix 14 – Nausea and Vomiting

ANTICIPATORY-medication-guideline.pdf (westmidspallcare.co.uk)

Algorithm for Nausea and Vomiting



Explanation & psychological support for patient/carers /family

Exclude treatable causes e.g. constipation, hypercalcemia, bowel obstruction

Consider strategies to keep away triggers e.g. strong smells

Levomepromazine 2.5mg -5mg PRN SC max 25mg/24hrs

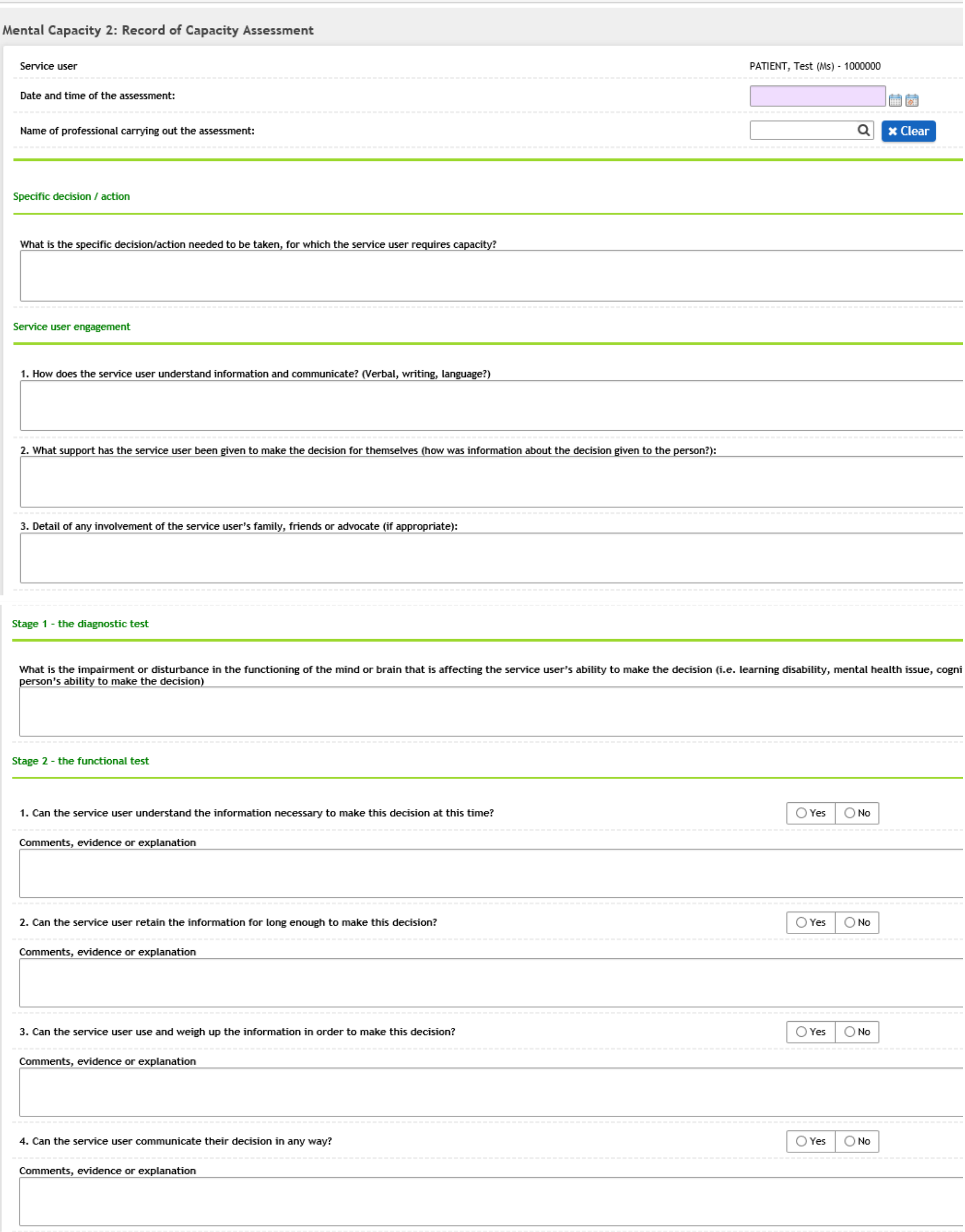
Continue with antiemetic in equivalent dose via CSCI route. (Seek specialist advice if needed re: appropriate dose)

Stop oral anti-emetics

Give levomepromazine 2.5mg-5mg SC

Review
If two or more doses are required over 24 hours consider starting a CSCI of levomepromazine over 24 hours.

Appendix 15 - Mental Capacity Form on Rio



Mental Capacity 2: Record of Capacity Assessment

Service user	PATIENT, Test (Ms) - 1000000
Date and time of the assessment:	
Name of professional carrying out the assessment:	

Specific decision / action

What is the specific decision/action needed to be taken, for which the service user requires capacity?

Service user engagement

1. How does the service user understand information and communicate? (Verbal, writing, language?)

2. What support has the service user been given to make the decision for themselves (how was information about the decision given to the person?):

3. Detail of any involvement of the service user's family, friends or advocate (if appropriate):

Stage 1 - the diagnostic test

What is the impairment or disturbance in the functioning of the mind or brain that is affecting the service user's ability to make the decision (i.e. learning disability, mental health issue, cogni
person's ability to make the decision)

Stage 2 - the functional test

1. Can the service user understand the information necessary to make this decision at this time? ○ Yes ○ No

Comments, evidence or explanation

2. Can the service user retain the information for long enough to make this decision? ○ Yes ○ No

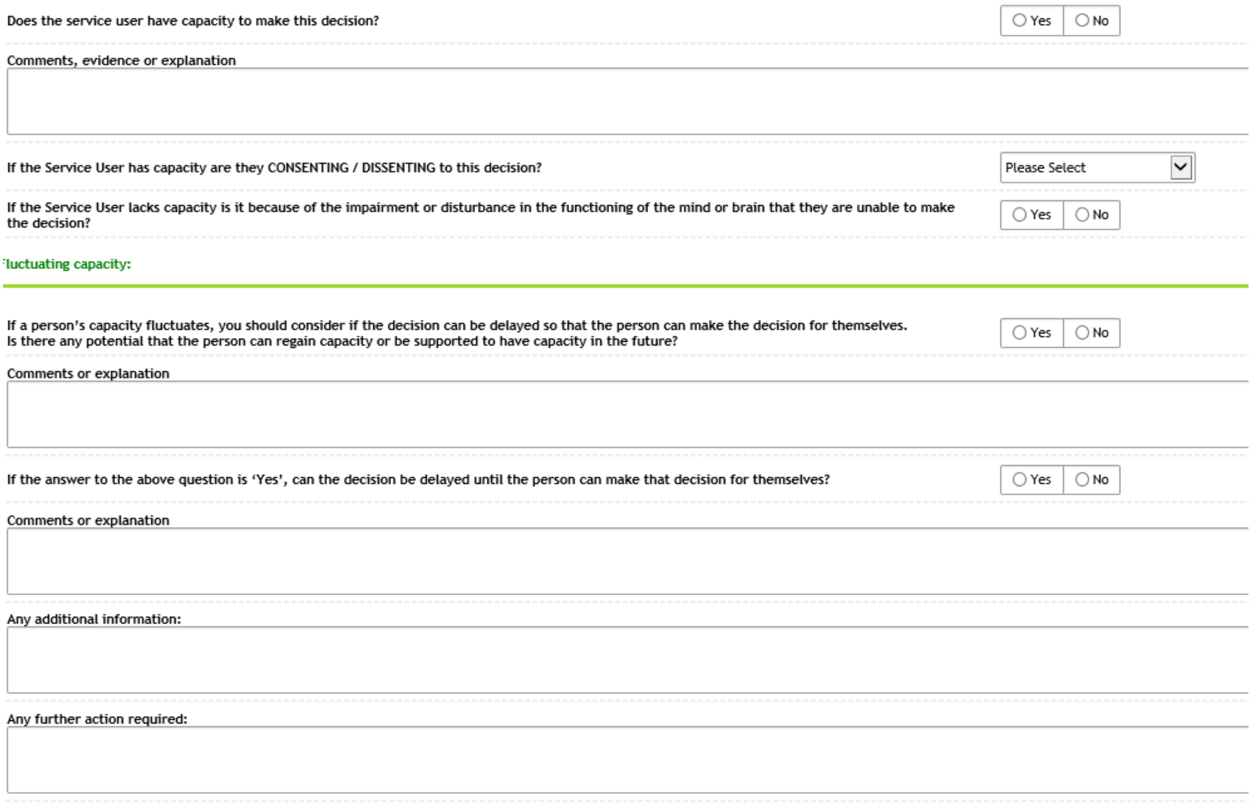
Comments, evidence or explanation

3. Can the service user use and weigh up the information in order to make this decision? ○ Yes ○ No

Comments, evidence or explanation

4. Can the service user communicate their decision in any way? ○ Yes ○ No

Comments, evidence or explanation



Does the service user have capacity to make this decision? ○ Yes ○ No

Comments, evidence or explanation

If the Service User has capacity are they CONSENTING / DISSENTING to this decision? Please Select

If the Service User lacks capacity is it because of the impairment or disturbance in the functioning of the mind or brain that they are unable to make the decision? ○ Yes ○ No

luctuating capacity:

If a person's capacity fluctuates, you should consider if the decision can be delayed so that the person can make the decision for themselves.
Is there any potential that the person can regain capacity or be supported to have capacity in the future? ○ Yes ○ No

Comments or explanation

If the answer to the above question is 'Yes', can the decision be delayed until the person can make that decision for themselves? ○ Yes ○ No

Comments or explanation

Any additional information:

Any further action required:

Appendix 16 – What to do when an unexpected death happens on the ward – managing the practicalities

STOP

Alarms activated – help is on the way
Resuscitation Policy applies unless DNAR instruction is known to be in place.
Nominate ONE member of staff to take charge of situation.

- **Summon additional help:**
  - Use medical emergency protocol and/or 999 ambulance
  - Bleep on-call medic and senior staff
  - Allocate staff to support service users and move if necessary
  - Call police if death is unexpected or there is any concern re cause.

If paramedics attend and death is confirmed, ask where the body will be taken and ensure this is clearly recorded.

Once death is confirmed:

- **Continue to maintain dignity**
  - Cover the body with a clean sheet
  - Wear gloves if required
  - Aim for a calm, quiet environment
- **Secure and/or screen the area**
  - Keep staff in area to a minimum
- **Unless absolutely necessary, <u>Do not touch the body</u>**
  - Do not remove any clothing, jewellery, articles of faith, etc (consult Culture, Faiths & Belief in Dying and Death)
- **Preserve the scene**
  - Leave everything exactly as you find it until authorised otherwise

THINK

- **Legal matters**
  - If detained under MHA, inform CQC
  - Decide if duty of candour applies
- **The next-of-kin / nearest relative**
  - Allocate someone to contact family/carer immediately, this can be ward or senior staff, plan what to say, do not use euphemisms
- **Consider requesting additional staff**
- **Meeting cultural/spiritual needs**
  - Ask next-of-kin and/or check records for faith affiliation and/or any advance statements
  - Consult Spiritual Care team and/or Culture, Faiths & Belief in Dying and Death
- **Other service users will know something has happened. Keep it simple and honest:**
  - Agree and document a plan about what will be said, when and what support is needed
  - Rio progress note all service users involved
- **Arrangements for undertaker**
  - Ask next-of-kin
  - Take culture / faith needs into account
  - Social services default is Bastock's (24/7: 0121 706 4040 – number correct as at 11/16)
- **If next-of-kin wish to attend**
  - Ensure private room is available, offer tea/coffee, have tissues, allocate staff.
  - Be aware distress may be increased if a loved one cannot be seen
  - Offer contact from spiritual care team
  - Ask for contacts details of preferred liaison person for on-going support / funeral details
  - Customer Relations **PALS 0800 953 0045**

ACT

Plan, allocate tasks and then act

Before the shift ends:

- **Pack the personal belongings** with dignity and store in a designated place
- **Arrange cleaning / infection control measures** if necessary
- **Eclipse incident log,** no names and only brief facts on the summary
- **Draft management report**
- **Gather staff for de-brief at end of shift**
  - Keep it simple, acknowledge challenges, encourage sharing, affirm feelings and thank one another
  - Signpost to support; PAM, Spiritual Care, clinical supervision.
- **Look after yourself**
  - Check back to reassure yourself you've done everything possible
  - Make a plan for your own support
  - Go off-duty and get some rest

Within three days, as appropriate:

- **Support for next-of-kin/family/carer**
  - Contact to offer a home visit/s by a senior clinician and/or spiritual care
  - Offer named contact to support collection of belongings.
- **Arrange on-going support**
  - Contact Spiritual Care for immediate support and memorial if appropriate
  - Ensure relevant clinicians are made aware of event, including CMHT etc

Appendix 17 - End of Life care plan (inpatient units) - step by step guide

Original author Jaqueline Webb and Leona Tasab

Patients will be placed on end-of-life care plan following an MDT discussion.

Patient's name …………………………………………………………

End of life care plan commenced on………………………………

Before death

- At no point throughout a patient's deterioration should a paramedic be called
- Give PRN medication as prescribed with any sign of pain, agitation, breathlessness or vomiting. There is no limit on how much can be given, however if they still have troublesome symptoms, seek advise - The prescribed medication should always be administered as dictated by patient symptoms. It is important to make sure that the patient is kept as comfortable as possible using medication and skilled care.
- Carry out frequent oral hygiene (moisten lips and gums with mouth swabs) only give food or fluids if there is no possibility of choking risk.
- Do not carry out physical health observations but alternate patient's position at appropriate intervals in an attempt to maintain skin integrity and comfort.
- Oxygen saturation monitoring is not required unless you need them to guide oxygen titration. Give patient oxygen through nasal cannula for comfort purposes as indicated/prescribed. Oxygen is indicated for low saturations not breathlessness, Morphine may be helpful for this.
- Change pad only if wet indicator shows change is required or soiled.
- Consider patient's spiritual wishes and aim to meet these. Review individual religious believes and requirements prior to death. Information is available on Connect
- Offer family frequent drinks and snacks and access to the garden if they visit. Reassure family that someone will stay with their relative if they need to leave the room.
- Remember the hospital setting may be alien to family so they may need support to understand what is happening and what is expected of them.

Considerations during the COVID 19 pandemic/infectious disease only –
- Ensure PPE visiting questions are asked and recorded on visiting form
- Ensure family are assisted to doff and don PPE as required (gloves, apron, fluid resistant surgical mask).

When a patient dies

- **Take a breath, death has happened there is no rush**
- Maintain the persons dignity by ensuring the body is cleaned, made as presentable as possible and cover with clean linen. Also review the room is presentable and tidy (including en-suite bathroom) – how they see their loved one at this point is a lasting memory for the family
- Comfort family if they are present and be sensitive but be specific (avoid euphemisms e.g., "he's gone to a better place")
- Contact ward/duty doctor to confirm death in Rio. Be mindful that the duty doctor may have other clinical priorities and although you will be concerned, the doctor will need to attend to patients requiring medical review first.

- Once death has been confirmed by the doctor, inform senior staff or on call manager of the expected death of a patient [*and whether Covid is confirmed*]. Also confirm whether the patient was informal or detained under Section of MHA.
- If the patient was forensically detained (Sec 37/41, 47/49) contact police and they will send an officer to the ward to confirm death and assess the scene. The body and surrounding area should not have been touched for any forensically detained patient or suspected suicide.
- Contact Bastocks the undertaker on 0121 706 4040 (unless family identify that they would prefer to use an alternative service provider, if that is the case clearly document the name, address, and telephone number of the undertaker on Rio). Do not request for the undertaker to attend until the family are ready to leave their relative.
- *[Confirm patient's COVID status with the funeral undertaker.]*
- **Prior to leaving the unit, take the name, location and any telephone numbers of the undertakers and any information the family may need and record in Rio**
- Make sure that if Bastocks is used, family are given the address and contact details of the funeral directors. (Some undertakers have more than one branch)
- Again, ensure the patient is clean and presentable and they are dressed in clean clothing.
- Attempt to close patient's eyes and mouth by placing wet cotton gauze on their eyes if they are unable to stay shut and position head by raising it so that the chin is tilted down towards the chest, which will help to close the mouth and reduce the risk of stomach reflux.
- Be mindful that there might be a change in skin colour and temperature
- Bowel and bladder contents may void so keep (fresh) continence pad in place
- Air may occasionally be expelled by the patient after death from the lungs, stomach, or bowels, although startling this is normal
- Record property remaining on the body
- If wearing any jewellery, please check with family if they would like this before the patient is taken to the undertakers. If family take any jewellery, please document / list in Rio
- Assist funeral undertakers to take patient's body out of the ward with dignity by reducing opportunity for other patients to see
- Always work in twos to support each other. If a learner who is third year or has been caring for the patient for a number of days wishes to take part as a learning experience, assess if they need to be a third person.
- Offer family the family support service email address **bsmhft.family.support@nhs.net** (Family will need patient's Rio number for that.)
- Explain to the family that a death certificate will be completed and issued within a maximum of five days, and we will liaise closely with them to arrange for it to be sent to the registry office (during pandemic) or for them to collect it (outside of pandemic).
- Ensure that you take time to support each other, acknowledge what's happened, affirm each others' feelings, and thank one another.
- Remember- caring for a patient in their final hours is a privilege and an honour.

Dealing with formalities

- Death of a patient requires an Eclipse form to be completed (classed as a Serious Incident if COVID related death).
- Death certificate is to be completed by the Responsible Clinician (or last doctor to see the patient alive) during the next working day
- Death certificate book is located in ________________. This is controlled stationary so checks must be performed.

- Transport may need to be arranged to transfer the book from stored location
- There is a book at Juniper (Rosemary) and Reservoir Court inpatient unit.
- Ensure that a record is made by the area sending the book of the last certificate number issued and the receiving ward informed. The receiving ward must check that this is still the last certificate used and confirm with the person who sent the death certificate book. This is controlled stationary so checks must be performed.
- Ensure confidentiality is maintained by using tamper proof bag following BSMHFT policies.
- If family have requested that the patient is cremated, then a second doctor (provided by the ward team) will need to visit the funeral directors to see the body and confirm death using the cremation form provided by the funeral directors. They are also confirming that there is no presence of pacemakers or other reasons which would prevent cremation. The funeral director keeps the cremation form.
- Once the death certificate (MCCD) has been completed by the doctor, advise family that this has been sent to Birmingham Registry office and arrangements can be made directly with them. The MCCD needs to be scanned in and emailed to RORegistrations@birmingham.gov.uk Ensure that the GMC number of the medic that has completed the form is on it.
- If the patient was detained, the clinical registered member of staff will need to inform CQC by completing and sending "Statutory notification Regulation 17, Care Quality Commission (Registration) Regulations 2009" form. (Care Quality Commission, 2013) (Care Quality Commission, 2021)
- Pack patient's belongings into an appropriate bag, ensuring that they are clean. Store safely and advise family that they are ready for collection at a time convenient to the family and ward. Consider any precautions
- Consider sending a condolences card to the family from the ward.

Senior staff are available for support and can be contacted (add times available with telephone numbers) and the on-call manager is available via switchboard:

Ward Manager –

Matron –

CNM –

Other Specialist practitioners (if appropriate) -

Psychological support is also available for any staff 24 hours a day and can be contacted via switchboard.

Appendix 18 - Mental health notifications | Care Quality Commission (cqc.org.uk)

Statutory notification

Regulation 17, Care Quality Commission (Registration) Regulations 2009

Death of a person using the service who is detained or liable to be detained under the Mental Health Act 1983

Care Quality Commission

Notification reference:	

Statutory notification about the death of a person detained or liable to be detained by the registered person under the Mental Health Act 1983
Care Quality Commission (Registration) Regulations 2009 Regulation 17

Guidance on the completion of this form is available at **www.cqc.org.uk**

You must provide information in the mandatory sections (marked*). Please also provide all other requested information and enter dates in the format **dd/mm/yyyy**.

Please do not include the name of any person in the form, other than the name of the person completing and submitting the form. Information on how CQC processes and protects personal information, and on the rights of data subjects, are published on our website at **http://www.cqc.org.uk/about-us/our-policies/privacy-statement**

Return the completed form to: **MH_notifications@cqc.org.uk**

1 The provider and location*

Service provider:			
Location reference number:			
Location name:			
Location address:			
Ward / unit			
Responsible clinician			
Form filled in by:		Date submitted:	
Contact for more information (where different):			
Telephone number:			
Email address:			

2 Level of ward or unit security*

Acute admission	☐	Psychiatric Intensive Care Unit	☐	
Low secure	☐	Medium secure	☐	
High secure	☐	Other	☐	

3 The person who died*

Name					
Unique identifier:	Date of admission:	Date of section:	Date of birth:	Age range:	< 12; 12–15; 16–17; 18–24; 25–34; 35–44; 45–54; 55–64; 65–74; 75–84; 85+; Unknown
				select	

4 Relevant section(s) of the Mental Health Act*

Section 2	☐	Section 3	☐	
Section 4	☐	Section 5 (2)	☐	
Section 5 (4)	☐	Section 37	☐	
Section 37 / 41	☐	Section 47	☐	
Section 47 / 49	☐	Section 136	☐	
Community Treatment Order	☐	Guardianship	☐	

Other	☐	Please specify:	

What was their physical and psychiatric diagnosis(es)?	

Did the person have capacity to consent to mental health treatment? Yes	☐	No	☐	
If yes, did they consent to mental health treatment? Yes	☐	No	☐	

5 Circumstances of the death*

Cause of death (where known):	Date of death (dd/mm/yyyy):	Time of death (hh:mm):

Date & time last seen alive by staff:	Date (dd/mm/yyyy):	Time (hh:mm):

Where did the patient die:

On a psychiatric ward or unit ☐ On a medical ward ☐

Other ☐ Please specify:

Did they die whilst on Section 17 leave?	**Yes**	☐	**No**	☐		
IF YES were they escorted?	**Yes**	☐	**No**	☐		
Did they die during an unauthorised absence?	**Yes**	☐	**No**	☐		
Was their death the expected outcome of an illness or physical condition?	**Yes**	☐	**No**	☐	**N/K**	☐
IF YES:						
when was their last medical consultation in relation to the illness or condition (dd/mm/yyyy)?						
were they receiving appropriate care and treatment?	**Yes**	☐	**No**	☐	**N/K**	☐
Is it suspected that the death was self-inflicted?	**Yes**	☐	**No**	☐	**N/K**	☐
Did they die within 7 days of an incident of self-harm?	**Yes**	☐	**No**	☐	**N/K**	☐
IF YES:						
when was the last incident of self-harm (dd/mm/yyyy)?						
Did they die within 7 days of the use of restraint?	**Yes**	☐	**No**	☐		
IF YES:						
when was restraint last used (dd/mm/yyyy)?						
Did they die within 7 days of seclusion or time out?	**Yes**	☐	**No**	☐		

Did they die within 14 days of receiving ECT?	**Yes**	☐	**No**	☐		
IF YES:						
when did they last receive ECT (dd/mm/yyyy)?						

Did they die within 30 days of surgery?	**Yes**	☐	**No**	☐		
IF YES:						
when did they last have surgery (dd/mm/yyyy)?						

Did they die during or within 7 days of a violent incident?	**Yes**	☐	**No**	☐	**N/K**	☐

Is the certified cause of death known?	**Yes**	☐	**No**	☐
If YES, what was it:				

Describe how the death occurred?

Was the death as a result of:				
Confirmed coronavirus?	**Yes**	☐	**No**	☐
Suspected coronavirus?	**Yes**	☐	**No**	☐

6 Duty of Candour

If this is a notifiable safety incident under the 'Duty of Candour' (Regulation 20 of the Regulated Activities Regulations 2014), have you notified the 'relevant person' about this incident?	**Yes**	☐	**No**	☐
If No: Please say what your plans are for doing so.				

7 Medicines*

Was the person taking any medicines? **Yes** ☐ **No** ☐
(This includes for both physical or mental disorders)

If YES:

Medicine	**Dose**	**Route**

Box will expand

Was the cumulative anti-psychotic dose within BNF limits? **Yes** ☐ **No** ☐ **N/A** ☐

Did the person die within 7 days of receiving rapid tranquilisation? **Yes** ☐ **No** ☐

8 Investigation by a coroner or the police*

Please note ALL deaths of patients detained in hospital under the Mental Health Act MUST be reported to the local Coroner immediately by the treating clinician.

When was the death reported to the coroner (dd/mm/yyyy)?

What is the name of the coroner's office?

Is the death subject to investigation by the police? **Yes** ☐ **No** ☐

If YES:

What is the name of the police force?

What is the police reference number (optional)?

9 Any other relevant information (optional)

Box will expand

10 Additional information about the person

Funding (this item for non-NHS services only)

Self funded	☐	NHS (whole or part)	☐	Local Authority (whole or part)	☐	
Name of funding authority/ies:						

Gender

Male	☐	Female	☐	
Not specified	☐			

Ethnicity

White				
British	☐	Irish	☐	
Other	☐			
Mixed				
White / Black Caribbean	☐	White / Black African	☐	
White / Asian	☐	Other mixed background	☐	

Asian				
Indian	☐	Pakistani	☐	
Bangladeshi	☐	Other Asian background	☐	

Black or Black British				
Caribbean	☐	African	☐	
Other	☐			

Chinese	☐	

Other				
Other	☐	Unknown	☐	

Disability

Physical	☐	Learning	☐	
Sensory	☐			

Religion / Belief

Baha'i	☐	Buddhist	☐	
Christian	☐	Hindu	☐	
Jain	☐	Jewish	☐	
Muslim	☐	None	☐	
Pagan	☐	Sikh	☐	
Zoroastrian	☐	Unknown	☐	
Other				

Sexual identity

Heterosexual / Straight	☐	Gay or Lesbian	☐	
Bisexual	☐	Other	☐	
Unknown	☐			