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End of Life?

A new approach to help you identify and support people experiencing homelessness whose health may be deteriorating

Presented by

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and Kate Thompsett

With thanks to

Dr Caroline Shulman: GP & Researcher for Homelessness & Inclusion Health. Clinical Lead for University College London Hospital Pathway Team

Niamh Brophy: Homeless Palliative Care Coordinator at St. Mungo's

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Housekeeping essentials

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Why ?

Equitable care: care that does not vary in quality because of personal characteristics, location or socioeconomic status

Equality: without discrimination

To improve palliative care for **Marginalised Groups** such as those Homeless or Vulnerably housed

Welcome to Martlets

NHS Sussex Community NHS Foundation Trust

- **Community Services** Hospice@Home, Clinical Nurse Specialists, Palliative Care Doctors,
  The Hub: 24 hour telephone support 01273 964164
- **Day Services** including complementary therapists, coffee mornings, allotment group
- **Inpatient Unit** 8 bedded inpatient unit currently at Maycroft Manor Nursing Home
- **Rehabilitation Team** Inpatient and community physiotherapists + occupational therapists
- **Patient & Family Support Team** Social Workers, Bereavement Counsellors, Chaplaincy, Carer Support & "Compassionate Neighbours"

COVID has changed the way some of these services are accessed to find out more
https://www.martlets.org.uk/

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Homeless Health Inclusion Team

- We are a Multi-Disciplinary Team providing Health Care both In-Reach to the Hospital and Outreach to vulnerably housed patients who are struggling to engage with mainstream health services
- Nursing and Therapies
- Part of Sussex Community NHS

  Foundation Trust

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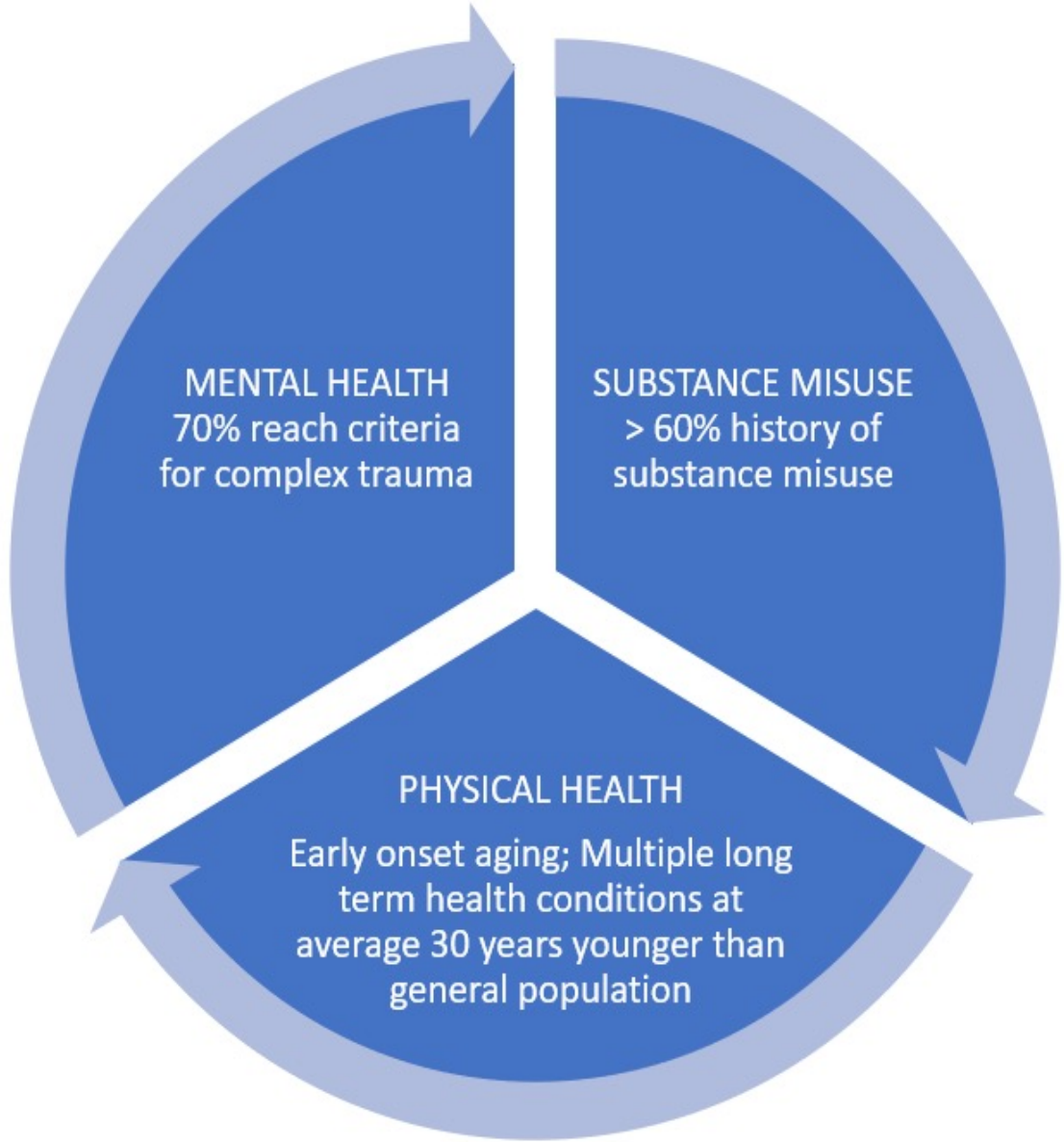
Tri-Morbidity of Complex needs



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Deteriorating Patient

Presented by
Caterina Speight
Clinical Nurse Lead and Manager SCFT
NHS Trust

- What are Red Flags

Physical indicators

- Decreased appetite and / or unintentional weight loss
- Not eating or drinking
- Generally frailer, increased lethargy, trouble mobilising, increased falls
- Breathlessness, memory or confusion issues
- Swollen abdomen, new or worse
- Unusual bleeding from nose, gullet, skin, rectum
- Using less or more drugs or alcohol, tolerating less
- Two or more unplanned hospital admissions in 6 months

Fresh blood or Black Poo

Women's health: change in menstruation/unexplained bleeding

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Emotional/Behavioural Indicators

- Increased fear/anxiety/afraid of being alone
- Social isolating and withdrawing from others
- Increased time spent in their room/bed
- Increased Anger or general moodiness
- Becoming dependent on others to buy their booze, drugs or shopping

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Case Study 1

- 23 yr Old male
- History of Schizophrenia, ADHD, Heavy Cannabis use, Polypharmacy, recently moved to new Supported Accommodation
- On Assessment presented with Agitation, High Anxiety, Confusion, memory issues, cuts to knuckles, Audible hallucinations, extensive bruising to hands and forehead, extremely thin/malnourished
- Causes of deteriorating Health?

Case Study 2

- Male 42
- History of Rough Sleeping recently accommodated in Supported Unit
- Symptoms included increased lethargy, asking others to buy alcohol, frequent nose bleeds, some memory issues (asking staff date and time) abdomen looks swollen, increase levels of self neglect, afraid of being alone inviting others to his room, complaining of blood in his poo.
- Causes of Deteriorating Health?

Long Term Effects of Drug Use

Cocaine/Crack: Heart, Lungs, Liver, Intestines/Bowel, Brain Impairment (Dementia)

Ketamine: Bladder, Kidneys, Brain, Vision

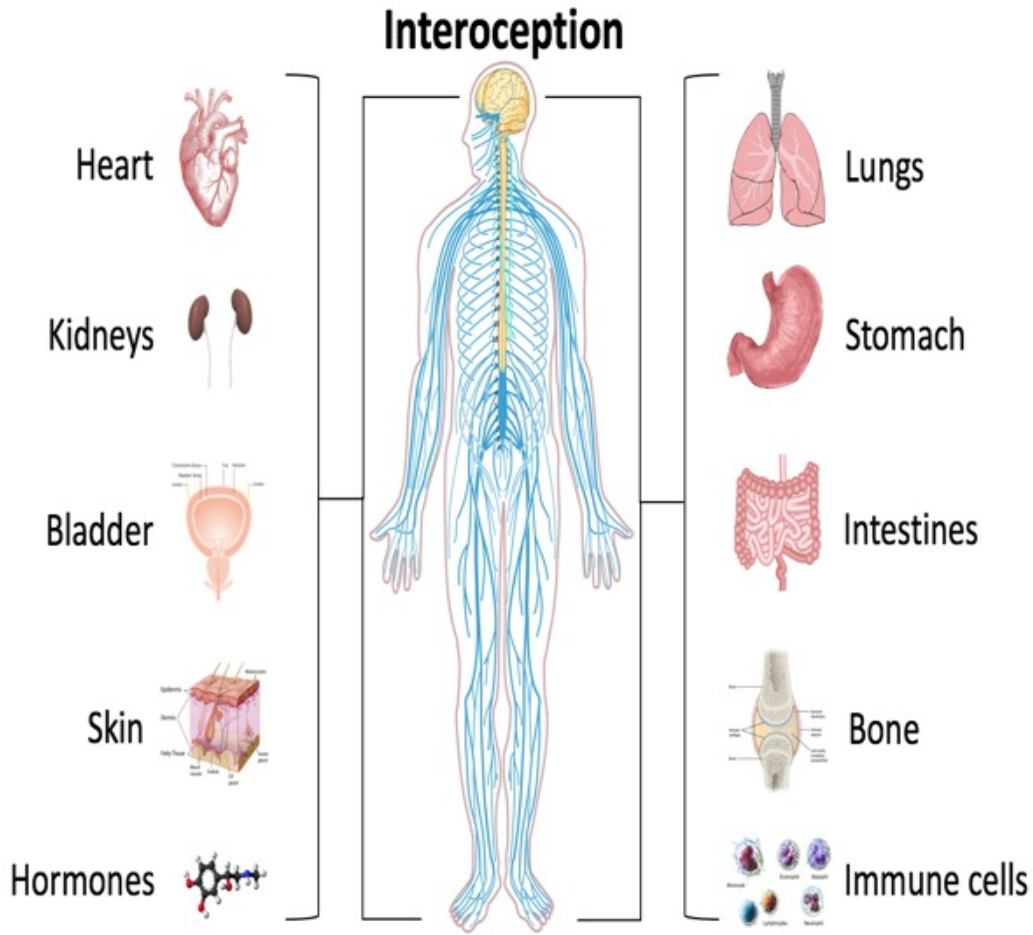
Heroin/**Opioids** such as fentanyl: Smoked/Injected long term lung conditons such as COPD, Lung Cancers. Lack of Oxygen to the brain and coma/brain damage, HIV, Hepatitis, Liver Cancers

Ecstasy and/or Molly/ MDMA: Increased Body Temperature (Hyperthermia) leads to muscle breakdown that can end in kidney failure

Cannabis/marijuana: Smoked/Edibles: Brain Impairment, Increased heart Rate, Heart Attack, Cancers

Methamphetamine: Crystal Meth: Stroke, Lung, Kidney and gastrointestinal damage, Brain Damage

Alcohol: Cancers: pancreas, liver, Heart Disease, Stroke, Brain Acquired Injuries, Brain Damage (Dementia) Liver (Cirrhosis) Oesophageal varices,



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Why Patients Deteriorate without Support

Complex needs & Access to healthcare:

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- People only seek treatment when problems reach advanced stage
- Danger of serious conditions being missed particularly in people who inject drugs (where unusual infections often deemed to be drug seeking)
- Challenging behaviour in mainstream services often from addictions not being addressed
- High rate of self discharge or unsafe discharge
- Where people are also battling with addictions and experience barriers to health care access, predicting when someone is approaching the end of their lives is often impossible.
- Consequently, many people die following crisis-led emergency admissions often with no opportunity for advance care planning.

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What is Palliative Care?

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

Palliative Care: easing or palliation of symptoms and suffering to feel more comfortable with improved quality of life. Months, sometimes many years

End of Life Care: care in the last days / weeks of life. Includes symptom management.

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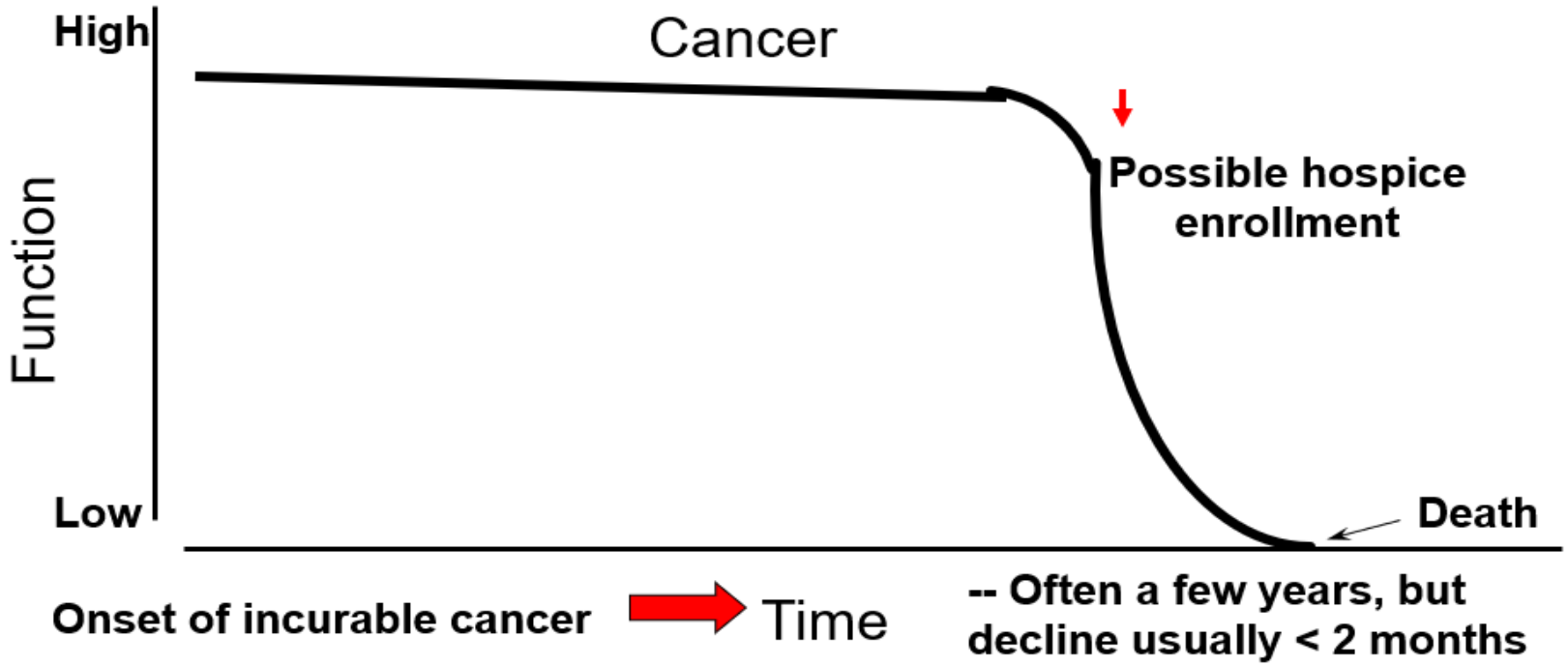
Cancer trajectory: (pattern of health over time) diagnosis to death



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Sepsis

Sepsis is a life threatening reaction to an infection

Symptoms:

- **S** Slurred Speech and Confusion
- **E** Extreme Shivering or muscle pain
- **P** Passing no urine (in a day)
- **S** Severe breathlessness
- **I** It feels like your going to die
- **S** Skin mottled or discoloured

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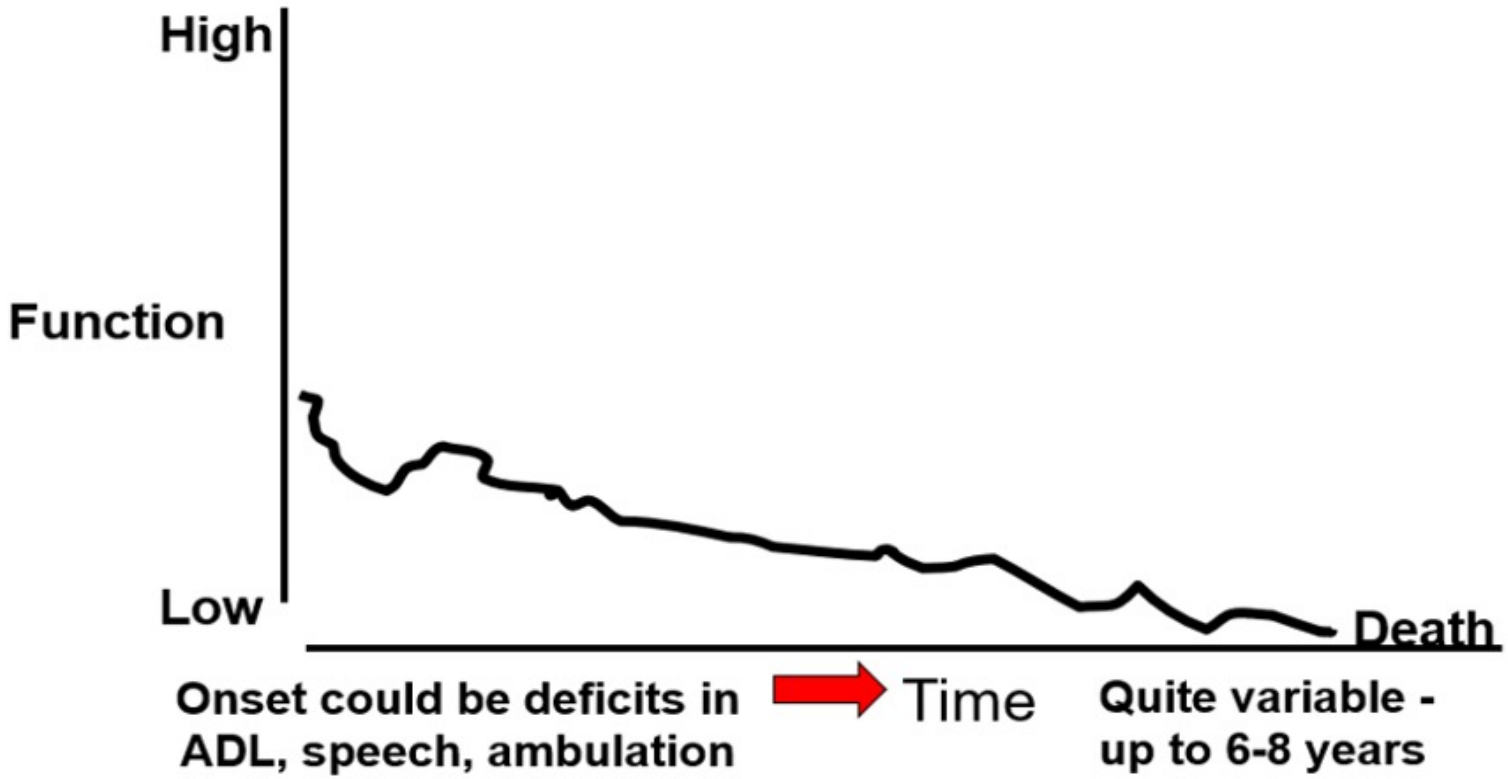
Dementia/frailty trajectory



Nature and cause of death

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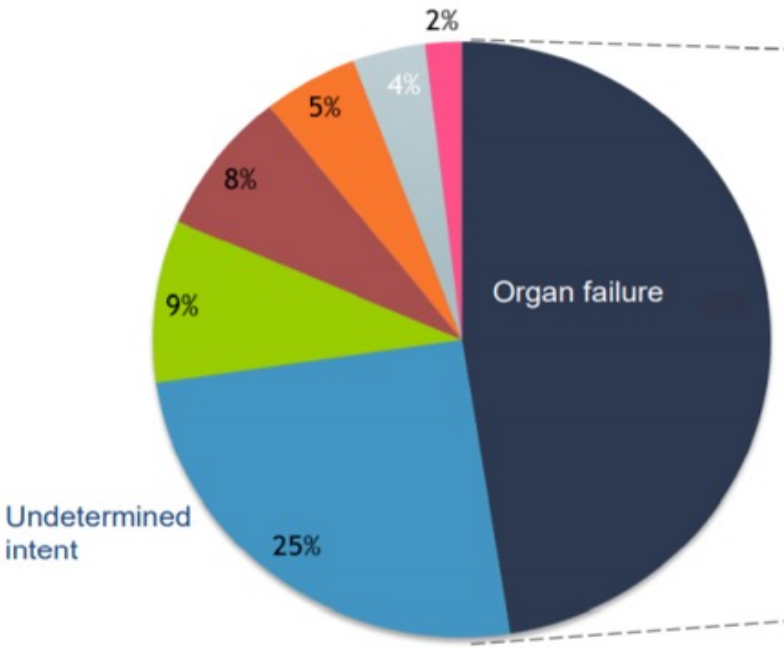
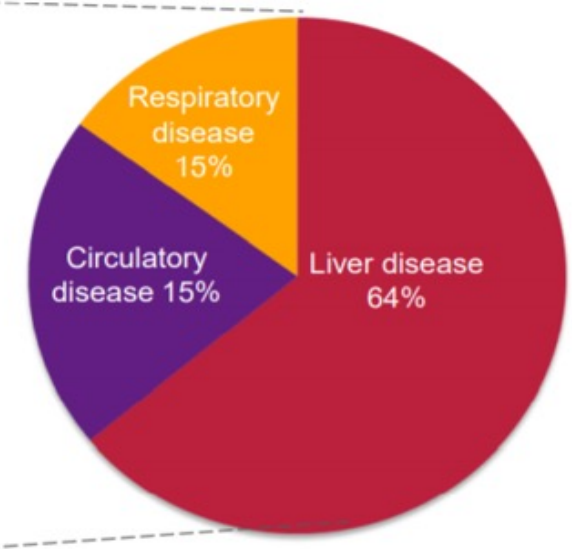
Primary cause of death



Multiple organ failure



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St Mungo's Jan 07 – May 17 (n = 421)

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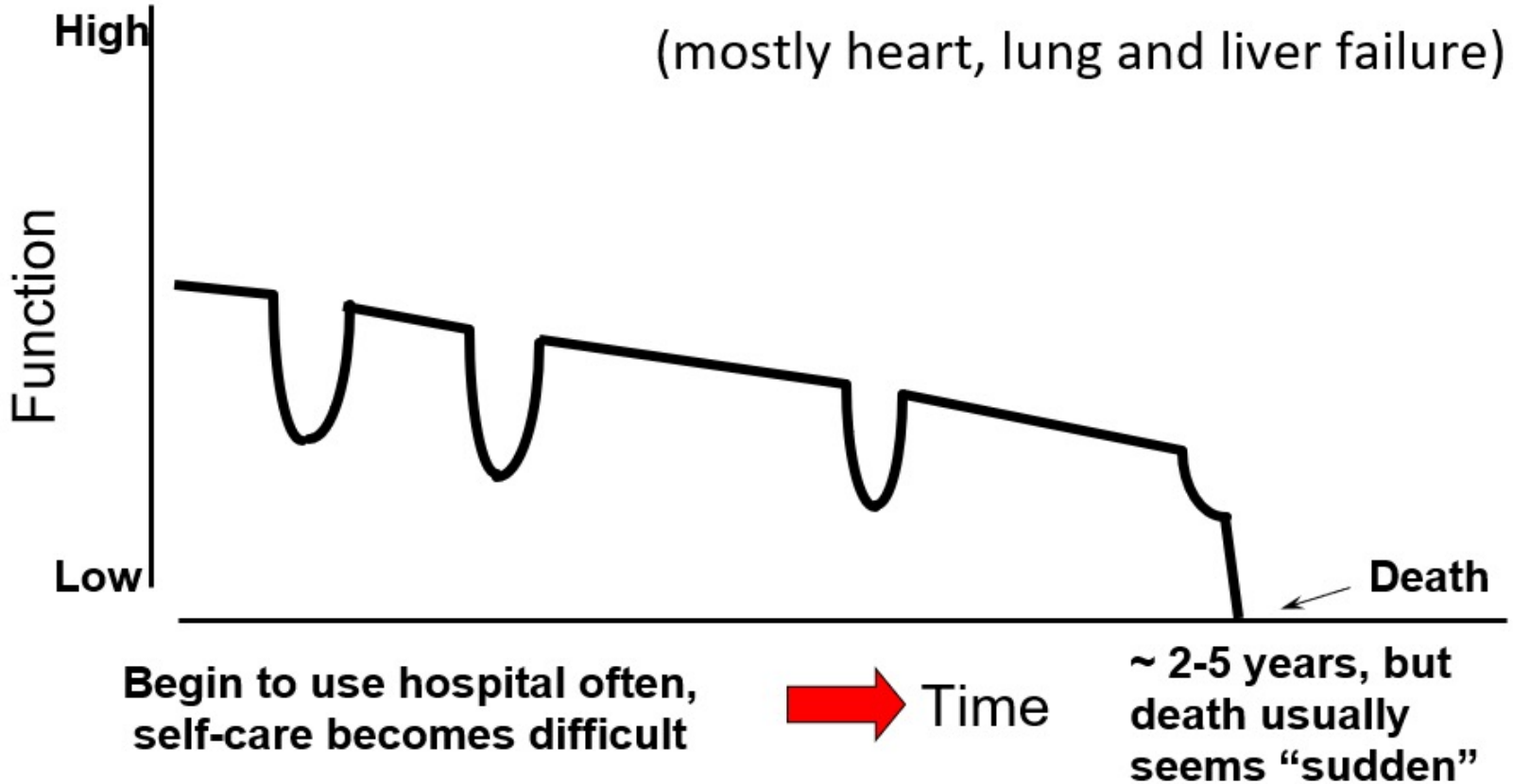
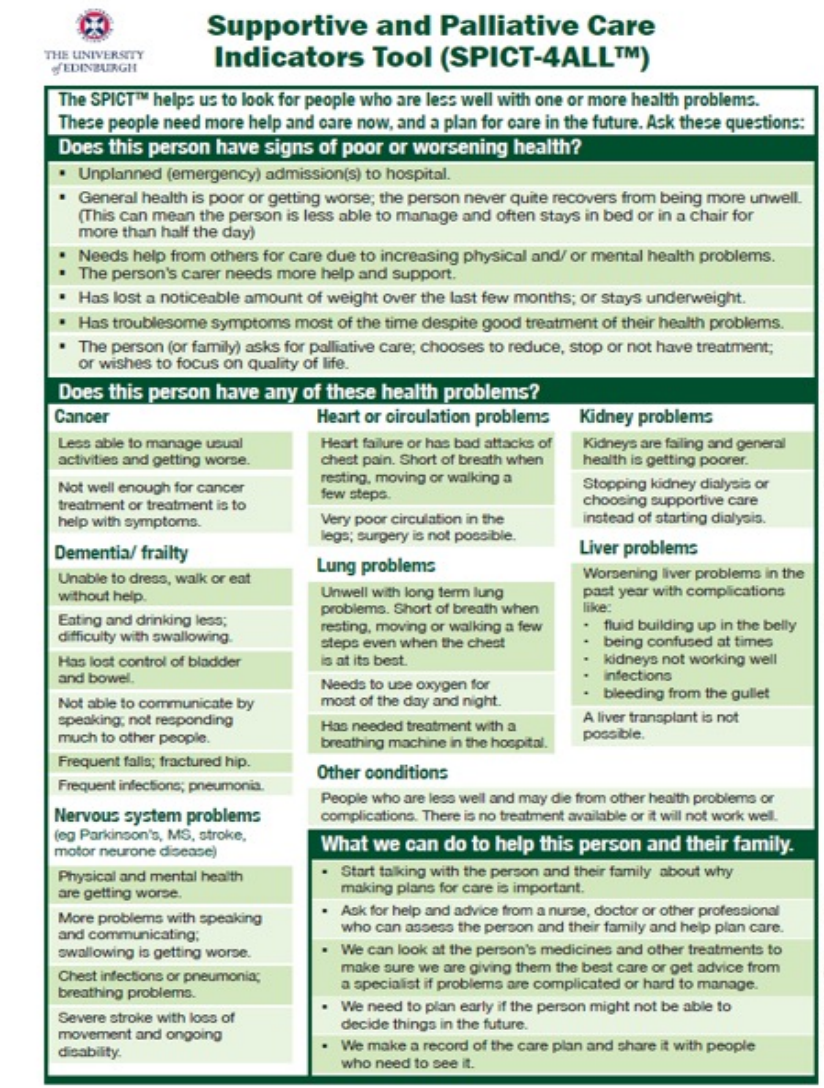
Organ system failure trajectory



SPICT-4ALL ‘APP’

‘The Gold Standards Framework’



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Supportive and Palliative Care Indicators Tool (SPICT-4ALL™)

The SPICT™ helps us to look for people who are less well with one or more health problems. These people need more help and care now, and a plan for care in the future. Ask these questions:

Does this person have signs of poor or worsening health?

- Unplanned (emergency) admission(s) to hospital.
- General health is poor or getting worse; the person never quite recovers from being more unwell. (This can mean the person is less able to manage and often stays in bed or in a chair for more than half the day)
- Needs help from others for care due to increasing physical and/ or mental health problems.
- The person's carer needs more help and support.
- Has lost a noticeable amount of weight over the last few months; or stays underweight.
- Has troublesome symptoms most of the time despite good treatment of their health problems.
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Does this person have any of these health problems?

Cancer

Less able to manage usual activities and getting worse.

Not well enough for cancer treatment or treatment is to help with symptoms.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Has lost control of bladder and bowel.

Not able to communicate by speaking; not responding much to other people.

Frequent falls; fractured hip.

Frequent infections; pneumonia.

Nervous system problems (eg Parkinson's, MS, stroke, motor neurone disease)

Physical and mental health are getting worse.

More problems with speaking and communicating; swallowing is getting worse.

Chest infections or pneumonia; breathing problems.

Severe stroke with loss of movement and ongoing disability.

Heart or circulation problems

Heart failure or has bad attacks of chest pain. Short of breath when resting, moving or walking a few steps.

Very poor circulation in the legs; surgery is not possible.

Lung problems

Unwell with long term lung problems. Short of breath when resting, moving or walking a few steps even when the chest is at its best.

Needs to use oxygen for most of the day and night.

Has needed treatment with a breathing machine in the hospital.

Kidney problems

Kidneys are failing and general health is getting poorer.

Stopping kidney dialysis or choosing supportive care instead of starting dialysis.

Liver problems

Worsening liver problems in the past year with complications like:

- fluid building up in the belly
- being confused at times
- kidneys not working well
- infections
- bleeding from the gullet

A liver transplant is not possible.

Other conditions

People who are less well and may die from other health problems or complications. There is no treatment available or it will not work well.

What we can do to help this person and their family.

- Start talking with the person and their family about why making plans for care is important.
- Ask for help and advice from a nurse, doctor or other professional who can assess the person and their family and help plan care.
- We can look at the person's medicines and other treatments to make sure we are giving them the best care or get advice from a specialist if problems are complicated or hard to manage.
- We need to plan early if the person might not be able to decide things in the future.
- We make a record of the care plan and share it with people who need to see it.

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

SPICT-4ALL™, June 2017

‘would I be surprised if this person were to die within the next six to 12 months?’

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If you can't predict, how do you plan?

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A shift in focus

End of life → Advanced ill health

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Palliative Holistic Care

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Case study: pain management challenges

44 years gentleman with Bone Cancer at the base of his skull

History of substance misuse but often denied: challenges in prescribing for pain relief

Childhood trauma / complex PTSD
History of anxiety & depression
Fear of hospitals and declined surgery

Total Pain
frequent attendances to A&E for uncontrolled Pain

Insecure hostel accommodation & his room was shut whilst he was in hospital

Discharged from hospital to a Nursing Home, away from hostel life

Advance Care Planning

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- A flexible **voluntary** process of discussion, to help them anticipate how their condition may effect them in the future
- Documentation of a person's wishes and preferences should they lack **capacity** and cannot make or communicate a decision for themselves
- A process that supports adults at any age or stage of health in **understanding** and **sharing** their **personal values**, **life goals** and **preferences** so future care is consistent with their wishes.

Barriers to Advance Care Planning

Lack of Confidence

Denial – from all sides

Concern about fragility & removing hope

Uncertainty of prognosis

Lack of options to offer

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(excluded due to age / behaviour / substance use)

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Parallel Planning approach

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Exploration of insights into illness, wishes and choices, Not just giving warnings -How to live well

Hoping for the best

Planning for the worst

Talking about what would happen should health get worse will not make it happen It may help people feel more in control.

- Early & repeated conversations
- Not just issues for the very end of life, but about living well
- Person centred - respecting choices even if we feel they are unwise

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Advance care Planning
(health and well-being)

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What you would like to happen
Advance Statement
Preferred Priorities for Care
Beliefs
Values
Daily routine
Likes/dislikes
Place of care
Any fears around treatment / care

What you would NOT like to happen
Advance Decision to Refuse Treatment
Legally binding but Solicitor not necessary
illness & treatment specific

Lasting Power of Attorney for health & welfare
'an Advocate'
Office of the Public Guardian (trumps ADRT)

DNACPR
Not likely to be successful
Consultant/GP
'Family'
Not legally binding

Doctor or Senior Nurse Recommended Summary Plan for Emergency Care and Treatment

Advance Care Plan
What is in place already?
Preferred place of care & dying
Made a Will
Care of pets
Spiritual
Funeral arrangements
Re-connect with family?
Organ donation
NOK / LPA

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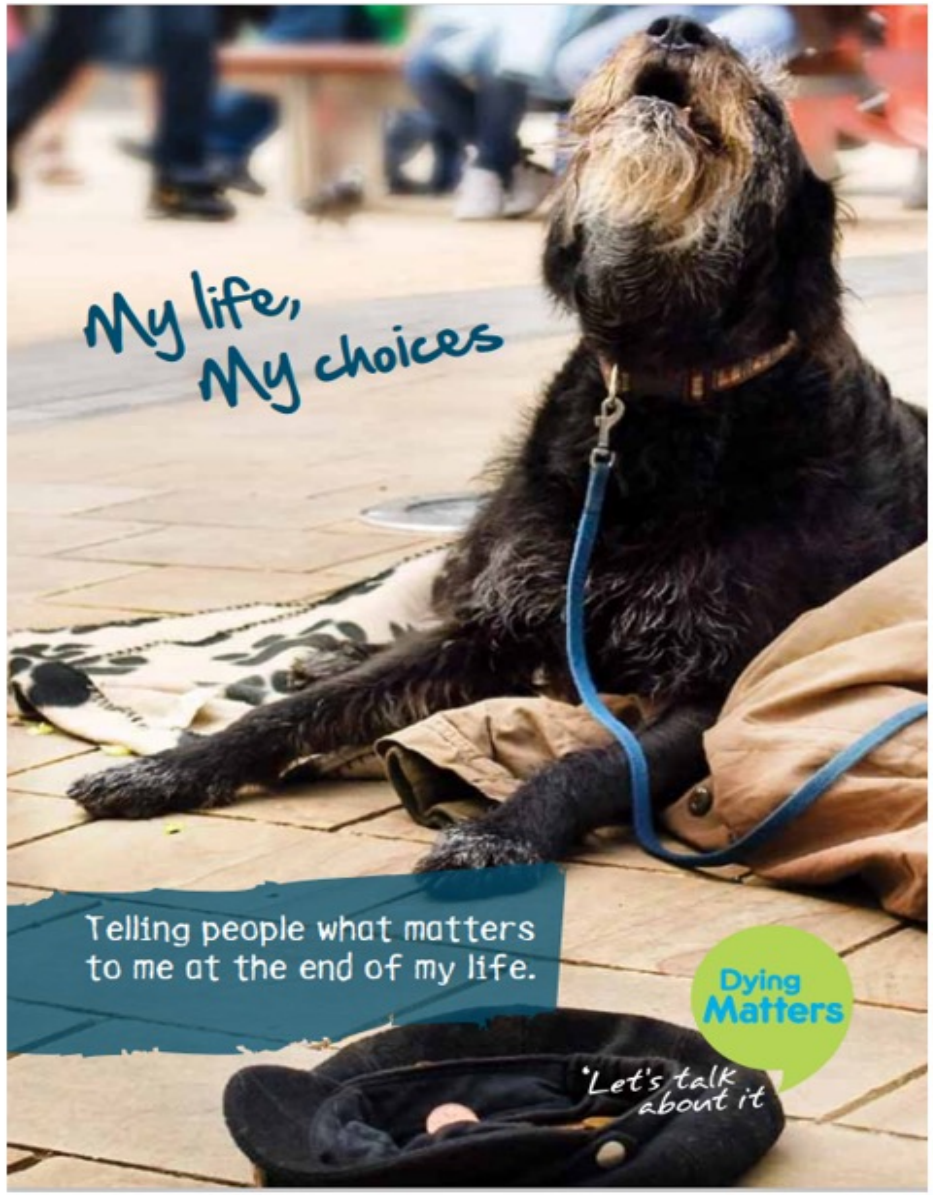

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Dying Matters
Let's talk about it

www.homelesspalliativecare.com

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What is ReSPECT?

- Recommended
- Summary
- Plan for
- Emergency
- Care and
- Treatment

Front

Back

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ReSPECT Recommended Summary Plan for Emergency Care and Treatment

1. This plan belongs to:

Preferred name	Full name
	Date of birth
Date completed	Address
	NHS/CHI/Health and care number

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

ReSPECT

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

Document the full capacity assessment in the clinical record.

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:**

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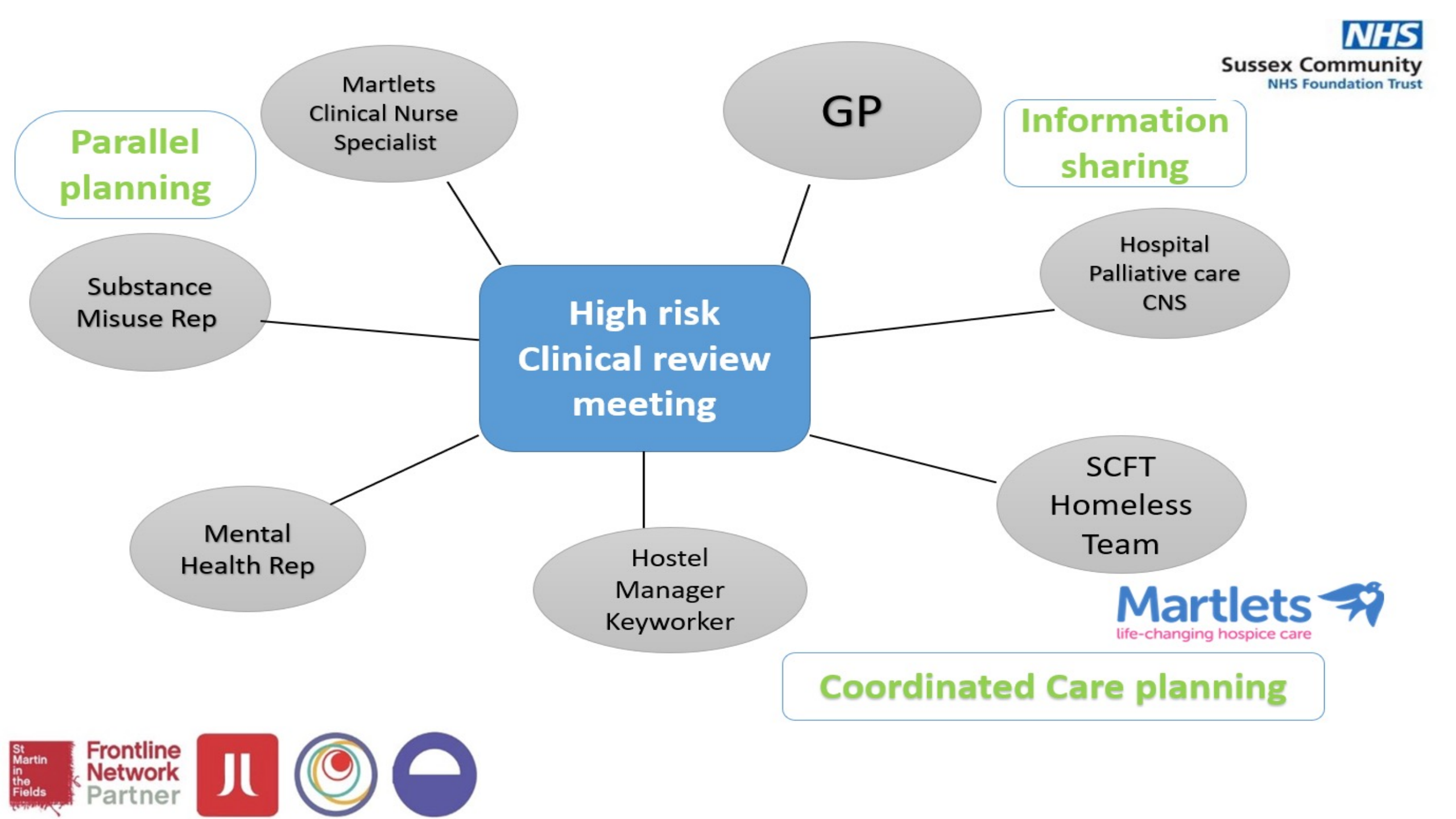
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Martlets Clinical Nurse Specialist
GP
Parallel planning
Information sharing
Substance Misuse Rep
Hospital Palliative care CNS
High risk Clinical review meeting
Mental Health Rep
Hostel Manager Keyworker
SCFT Homeless Team
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Coordinated Care planning
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Consent for Palliative Care Support

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Staff are concerned about advanced ill health?

Somebody from the Homeless Team would like to come and see you. Is that OK?

SCFT Homeless Health Inclusion Team **07341 049499** or **01273 265975**

They can consider if referral to Martlets Community Team for Specialist palliative care support is required.

Can we support you to see your GP?

GP can make a referral to the Martlets Community Team as well as Hospital Teams

Martlets advice is always available for patients on our caseload, as well as their families / advocates and carers 24 hours /day; 7 days /week

01273 964164

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REFERENCES

Homeless Palliative Care Toolkit
http://www.homelesspalliativecare.com/

My life, My choices
https://www.dyingmatters.org/sites/default/files/user/images/Resources/Promo%20materials/Public_Homeless_Leaflet%20WEB_1_.pdf

End of life choices
https://www.dyingmatters.org/sites/default/files/user/images/Resources/Promo%20materials/Staff_Homeless_Leaflet%20WEB_1_.pdf

SPICT-4ALL
https://www.spict.org.uk/spict-4all/

Homelessness and End of Life Care
https://www.mungos.org/app/uploads/2017/08/homelessness-and-end-of-life-care-resource-pack.pdf

Homeless Link 'The unhealthy sate of homelessness' 2014
https://www.homeless.org.uk/sites/default/files/site-attachments/The%20unhealthy%20state%20of%20homelessness%20FINAL.pdf

Supporting people with advanced liver disease approaching end of life 2011
https://www.mariecurie.org.uk/globalassets/media/documents/commissioning-our-services/current-partnerships/st-mungos-supporting-homeless-may-11.pdf

Premature frailty, geriatric conditions and multimorbidity among people experiencing homelessness: a cross-sectional observational study in a London hostel
https://www.emerald.com/insight/content/doi/10.1108/HCS-05-2020-0007/full/pdf?title=premature-frailty-geriatric-conditions-and-multimorbidity-among-people-experiencing-homelessness-a-cross-sectional-observational-study-in-a-london-hostel

A second class ending: Exploring the barriers and championing outstanding end of life care for people who are homeless
https://www.cqc.org.uk/sites/default/files/20171031_a_second_class_ending.pdf

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