Beyond Protocol: Personalised preparation and parallel planning for transplant and cellular therapy

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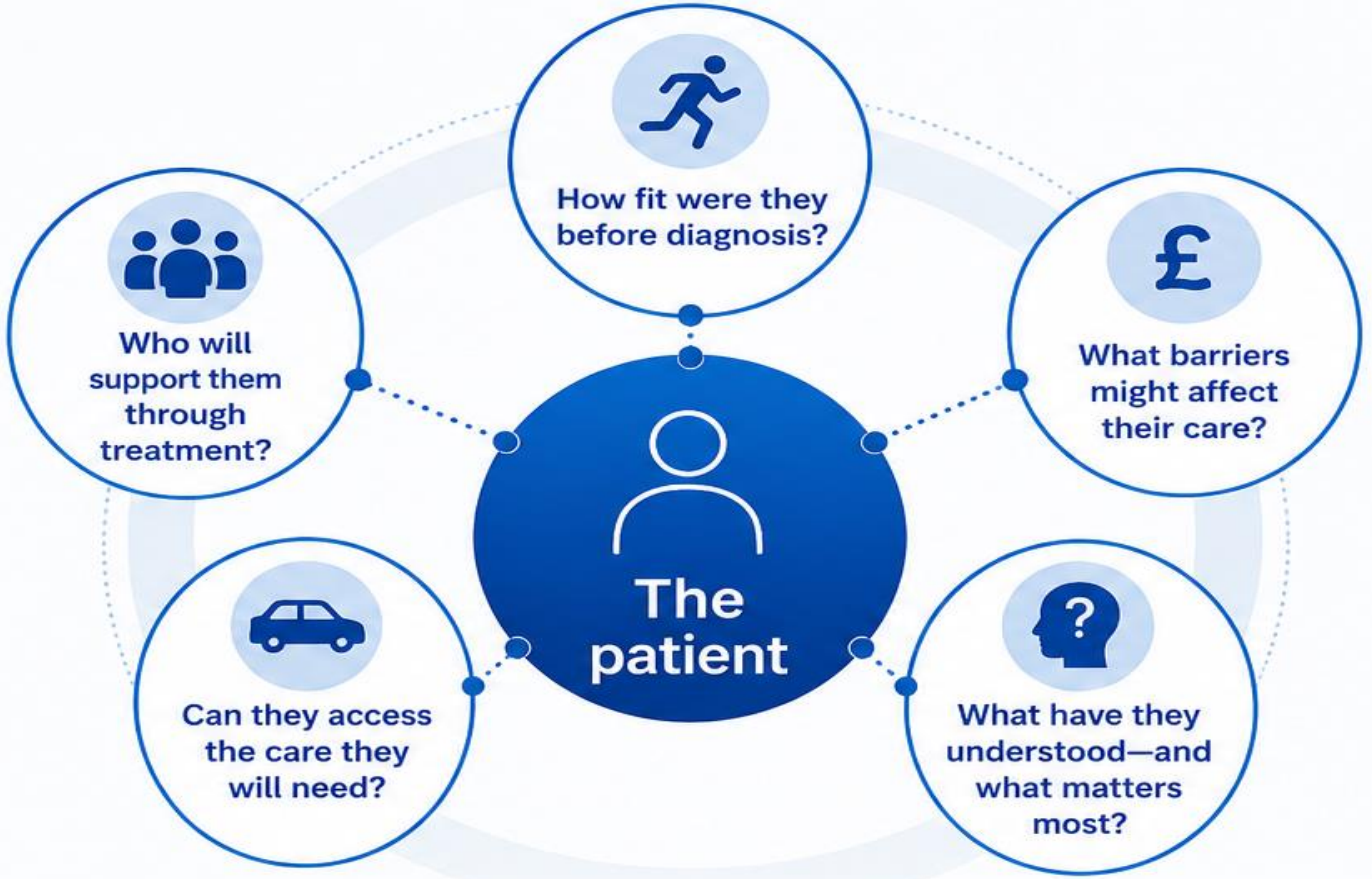
Let’s get personal

Personalised care starts before the consent conversation.

Understanding the person before discussing the treatment.

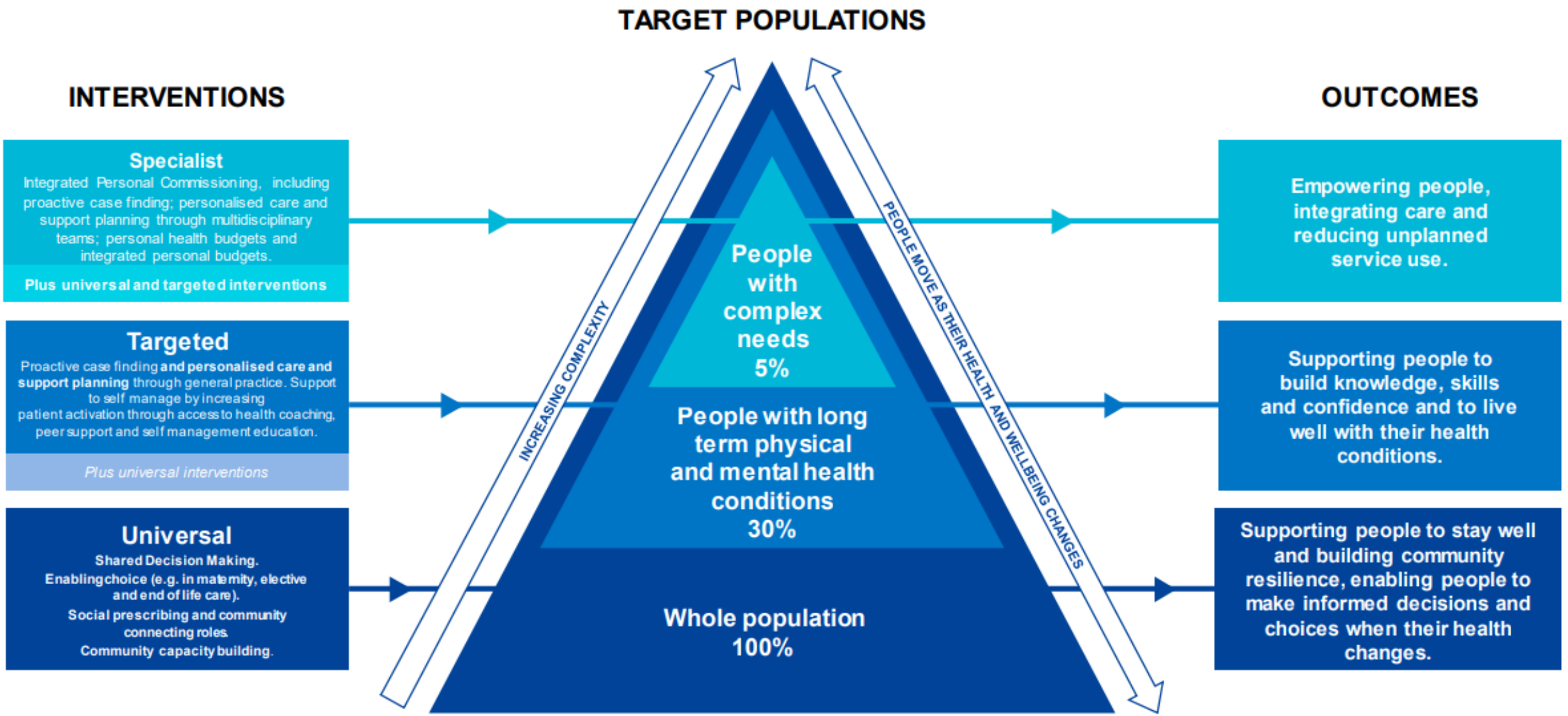


These factors influence treatment decisions, preparation for therapy, recovery and survivorship.

Comprehensive Personalised Care Model

All age, whole population approach to Personalised Care

NHS England



https://www.england.nhs.uk/wp-content/uploads/2019/01/universal-personalised-care.pdf

We all know the risk statistics...

Cure is possible – but every path carries risk

AUTO

POTENTIAL CURE
- TRM no higher than 3%
- Lymphoma ~50% cure/relapse
- MM 3–4 years EFS

POTENTIAL HARM
- Infection

POTENTIAL LONG-TERM CONSEQUENCES
- May not be definitive treatment
- Relapse

ALLO

POTENTIAL CURE
- TRM 15–20%
- Lymphoma ~50% cure
- MM ~30% relapse

POTENTIAL HARM
- Infection
- GVHD
- Incomplete, delayed immune reconstitution
- Immune-mediated complications

POTENTIAL LONG-TERM CONSEQUENCES
- Life-changing chronic conditions

CAR-T

POTENTIAL CURE
- TRM ~5%
- Lymphoma 40–54%, 69–74% (depending on disease)
- MM 30–60% relapse

POTENTIAL HARM
- ICANS/CRS
- Infection

POTENTIAL LONG-TERM CONSEQUENCES
- B cell aplasia
- Relapse

Complex decisions. Profound trade-offs.

- Risk of death
- Chronic morbidity
- Prolonged hospitalisation
- Impact on family
- Employment
- Fertility
- Identity
- And more...

* A comprehensive analysis of the fatal toxic effects associated with CD19 CAR-T cell therapy - PMC (nih.gov)
** Long-term outcomes following CAR T cell therapy: what we know so far | Nature Reviews Clinical Oncology
*** Mechanisms of Relapse After CD19 CAR T-Cell Therapy for Acute Lymphoblastic Leukemia and Its Prevention and Treatment Strategies - PubMed (nih.gov)

Personalised Care and Support Planning (PCSP) Clinic

A structured, pre-treatment appointment for all patients preparing for allogeneic transplant or CAR-T therapy.

Co-designed with BMT and cellular therapy patients

Grounded in lived experience and what matters most.

The right time

Held several weeks before admission—after eligibility is confirmed but before the intensity of conditioning and inpatient care.

The right space

Delivered in a non-clinical environment, such as Maggie's or the Macmillan Centre. A deliberate shift from procedure-focused to person-focused.

People are encouraged to bring

family members or friends—recognising that this is rarely an individual decision and that support systems are critical to successful transplant and survivorship.

What we deliver

Building relationships and therapeutic alliance

Creating time and space to listen, understand and build trust—foundations for shared decisions and optimal outcomes.

- Holistic needs assessment (HNA)
- Prehabilitation and health optimisation
- Advance care planning (ACP)
- Education and preparation
- Shared decision making
- Comprehensive geriatric assessment (CGA) / frailty assessment

For many patients, this is the first opportunity to pause and reflect on what undertaking high-risk therapy means—not just medically, but socially, psychologically, and practically.
We explore what matters to them, their concerns, and how we can tailor the pathway accordingly.

Evidence into practice

Emerging evidence supports structured, pre-treatment personalised care.

Evidence-informed
Grounded in published evidence and patient experience.

Understanding the need

Stenson et al. 2023

- Psychological morbidity
- Prognostic uncertainty
- Supportive care needs
- Needs begin at referral

Testing the intervention

Tate et al. 2022

- ACP clinic feasible
- High uptake
- High acceptability
- Early planning valued

Patients preparing for cellular therapy experience significant psychological and supportive care needs **early in the pathway.**

Translating evidence into practice

Personalised Care & Support Planning Clinic

- Holistic needs assessment
- Shared decision making
- Advance care planning
- Comprehensive geriatric assessment
- Prehabilitation
- Education and preparation

Structured, anticipatory interventions are **feasible, acceptable and valued** by patients and healthcare teams.

Our clinic combines these strands of evidence to **improve preparedness**, support **informed decisions** and **strengthen the therapeutic alliance** before treatment begins.

From referral to readiness

Preparing patients for treatment—earlier, together and proactively.

CNS-led and delivered with the whole MDT

01 First consultation

- Introduce PCSP clinic
- Provide “Getting to Know You” booklet
- Explain the pathway and next steps

02 Reflection at home

- Patient completes Holistic Needs Assessment at their own pace
- Space to reflect, consider what matters, and involve family if they wish

03 Preparation before admission

- CNS reviews HNA at apheresis
- Early MDT referrals (PT/OT, dietetics, psychology, palliative care etc.)
- Book dedicated PCSP appointment (few weeks before admission)

04 Readiness for treatment

- Face-to-face PCSP consultation (with family encouraged)
- Individualised care plan
- Prehabilitation and symptom optimisation
- Advance care planning (where appropriate)

The principle is **anticipation rather than reaction**— identifying risk early, coordinating support early, and preparing patients more comprehensively before treatment begins.

1. Who are the most important people in your life?

(How often do you see them and what do you like to do together? This could be partners, family, friends, or pets!) PARTNER - STUART - SEE MOST DAYS. DAUGHTER VANESSA EVERY WEEK MORE IF NEEDED SON TIM - EVERY 10 DAYS - MORE IF NEEDED - WIFE MARIA HER PARTNER MARK GRANDCHILDREN: GREAT GRANDCHILDEN STUARTS DAUGHTER NATALIE - PARTNER SIMON - 2 CHILDREN

2. What makes a good day for you?

(What is a good day like, who is it with, what would you do?) PARTNER SEASIDE - WALK ON BEACH, PADDLE, TEA + CAKE. MEET FAMILY SOMETIMES. HENGISTBURY. NATIONAL TRUST, FAMILY MEET UP, FRIENDS VISIT. WALK IN WOODS (MICHELDEVER)

3. When you're having a bad day what makes it better?

(Think about what you and others do that can help if you are having a bad day) PHYSICALLY VERY TIRED OR MIGRAINE OR HEADACHE. REST OR WALK FEELING LOW - WALK, TALK / FACETIME FAMILY OR FRIENDS.

4. What are the daily or weekly things you enjoy?

(Think about the important activities and routines that you have) ZOOM MEDITATION MONDAY P.M. ZOOM CHURCH SUNDAY + WEDNESDAY MORNING 1/2 HR. OUTDOORS, WALK - SOME DAYS. TESCO DELIVERY - THURS. READING, WATCH T.V. CROSSWORDS, WORDLE (MOST DAYS)

5. What do you think the people who know you well would say your best qualities are?

(For example, your sense of humor, honesty, kindness, and loyal friendship) GRANDCHILDREN ON PEBBLE - CARING, LOVING, GENTLE, FUN. DEVOTED TO FAMILY + FRIENDS. GOOD LISTENER, GOOD CONFIDANT INSIGHTFUL

Getting to know you document

6. Your worries and concerns

Tick any of the following options that are concerns for you:

Physical concerns	
	Breathing difficulties
	Passing urine
✓	Constipation CHEMO - BOWEL BLOCKAGES.
✓	Diarrhea CHEMO
	Eating, appetite and taste
✓	Indigestion SPASMS RESULT OF CHEMO
	Swallowing
✓	Sore or dry mouth or ulcers CHEMO '22 (CORSYDLE)
✓	Nausea or vomiting CHEMO + RADIO / LEVOMEPROMAZINE 1/4, V. BAD CHEMO '22
✓	Tired, exhausted, or fatigued DURING TREATMENT & RECOVER : LYMPHOMA RETURN
	Swelling
	High temperature or fever
	Moving around (walking/mobility)
	Tingling in hands or feet
✓	Pain or discomfort BACK PAIN - REDUCED NOW BACK DURING RADIO
✓	Dry, itchy, or sore skin HEAD & BACK : SHINGLES POST CHEMO 2020
	Changes in weight
	Wound care
✓	Memory or concentration (neurological concerns) CHEMO '22 MENTAL FOG
	Sight or hearing HAVE HEARING AID LEFT EAR IF NEEDED (CHEMO '22)
	Speech or voice problems
	My appearance
✓	Sleep problems DIFFICULTY SLEEPING SOMETIMES
	Sex, intimacy, or fertility
✓	Other medical conditions MIGRAINE (OCCASIONAL) PREVENTIVE MEASURE
	~~Other~~ : UTI's - PREVENTIVE MEASURES.

Practical concerns	
	Taking care of others
	Work or education
	Money or finance
	Travel
	Housing
	Transport or parking
	Talking or being understood
✓	Laundry or housework DO MUCH AS I CAN, WANT TO DO MORE.
	Grocery shopping TESCO DELIVERY
	Washing or dressing
✓	Preparing meals or drinks WITH WHAT I CAN : WANT TO DO MORE STUART COOKS WHEN I'M TIRED
	Pets
	Difficulty making plans
	Smoking cessation
	Problem with alcohol or drugs
✓	My medication LIST ATTACHED
	Other:

[No Title]

Family or relationship concerns	
✓	Partner NOT SEEING HIS FAMILY / WE ACTED ON ADVICE
✓	Children NOT ABLE TO JOIN FAMILY EVENTS
✓	Other relatives or friends GRANDCHILDREN LESS CONTACT THAN WOULD LIKE
	Person who looks after me
	Person who I look after
	Communicating with my loved ones - USE FACETIME ; PHONE etc.
	~~Other~~: COVID LOCKDOWN THEN REDUCED IMMUNITY CREATED LOSS OF MUCH CONTACT. SEE PEOPLE OUTDOORS IF POSSIBLE

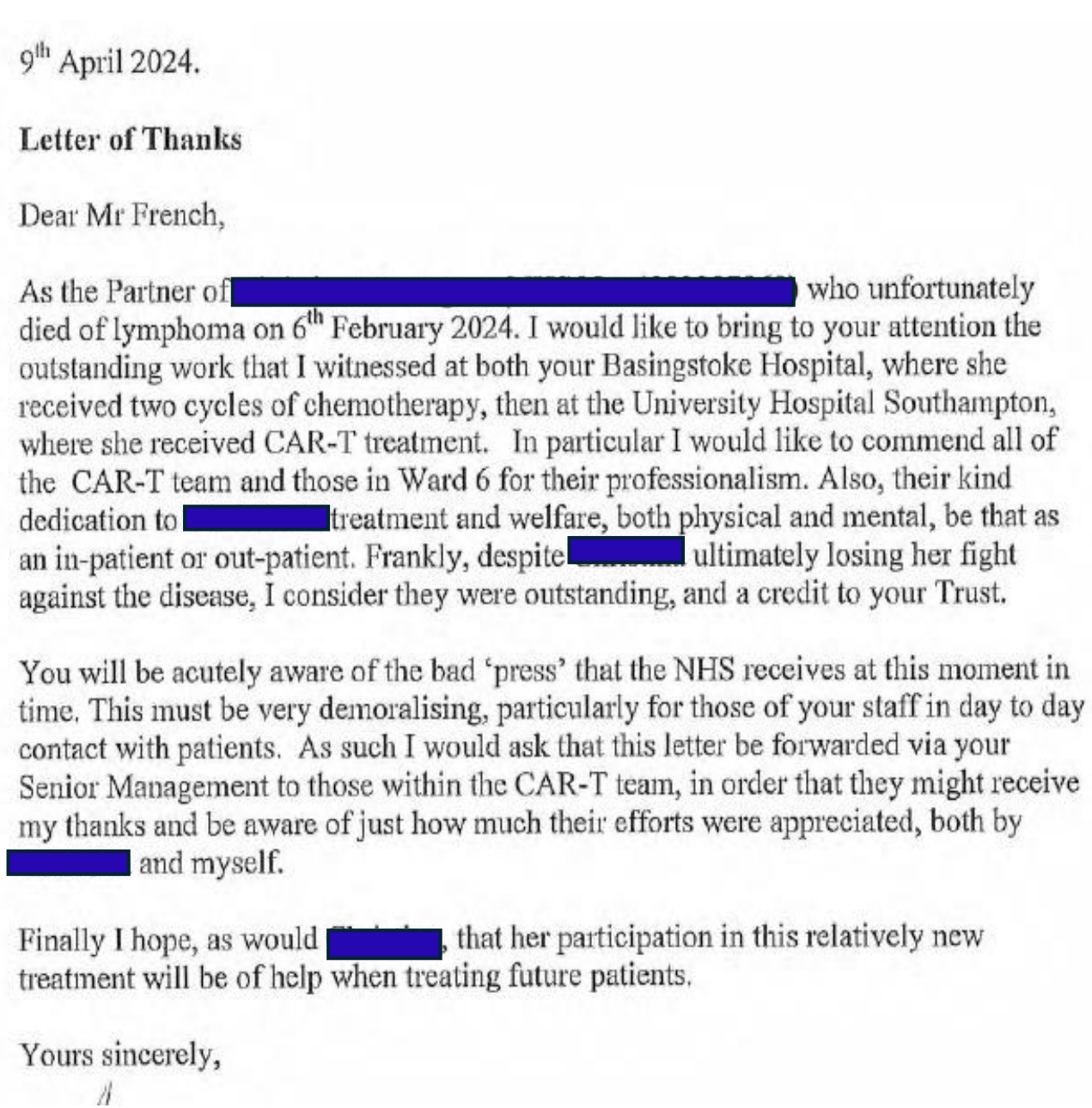
Health Needs Assessment

- Thinking about the future
- Parallel planning

The thoughts of the patient

''The advance care plan information and creation was so beneficial to me. At 78 years old I already had a will and lasting power of attorney in place. The information and support given to me made me consider things I would never have thought about. Since then, I have shared passwords to online accounts with my family and I have written letters to my children.''

(patient)



9th April 2024.

Letter of Thanks

Dear Mr French,

As the Partner of [redacted] who unfortunately died of lymphoma on 6th February 2024. I would like to bring to your attention the outstanding work that I witnessed at both your Basingstoke Hospital, where she received two cycles of chemotherapy, then at the University Hospital Southampton, where she received CAR-T treatment. In particular I would like to commend all of the CAR-T team and those in Ward 6 for their professionalism. Also, their kind dedication to [redacted] treatment and welfare, both physical and mental, be that as an in-patient or out-patient. Frankly, despite [redacted] ultimately losing her fight against the disease, I consider they were outstanding, and a credit to your Trust.

You will be acutely aware of the bad 'press' that the NHS receives at this moment in time. This must be very demoralising, particularly for those of your staff in day to day contact with patients. As such I would ask that this letter be forwarded via your Senior Management to those within the CAR-T team, in order that they might receive my thanks and be aware of just how much their efforts were appreciated, both by [redacted] and myself.

Finally I hope, as would [redacted], that her participation in this relatively new treatment will be of help when treating future patients.

Yours sincerely,

And her partner

Understanding frailty

More than age—about physiological and psychological resilience.

Frailty is a syndrome of diminished physiological reserve—**reduced strength, endurance**, and **resilience**—which **increases vulnerability** to stressors and adverse outcomes.

Physiological vulnerability does not map neatly onto chronological age.

We treat patients across a **wide age range.**

Why it matters

- Influences toxicity risk and recovery trajectory
- Impacts length of stay and risk of deconditioning
- Associated with morbidity and survival
- Essential for personalised treatment planning

Frailty is multifactorial

- Cumulative chemotherapy exposure
- Disease burden
- Malnutrition
- Sarcopenia
- Psychological stress
- Polypharmacy
- Social isolation
- Reduced functional capacity

Changing the question

How old is this patient?

vs.

How resilient is the patient to the physiological AND psychological insult we are about to deliver?

Considering frailty helps us **identify vulnerable patients** who need additional support—and recognise **robust patients**, regardless of age, who can benefit from intensive therapies.

Introduction Comprehensive Geriatric Assessment (CGA)

A structured approach to assessing resilience in BMT and CAR-T

CGA is a multidimensional assessment that evaluates medical, functional, psychological and social factors to understand a patient's physiological reserve, vulnerability and ability to tolerate intensive treatment.

How we introduced CGA into our PCSP pathway

Evidence

- Literature review
- EBMT benchmarking
- BSBMTCT outcome reports
- Learning from M&M meetings

Collaboration

- Medicine for Older People
- Physiotherapy
- Occupational therapy
- CNS training

Tools & Process

- Grip strength dynamometers
- Standard Operating Procedure (SOP)
- Integrated into PCSP appointments

Implementation

- Workforce training and competency
- Governance and quality assurance
- Practical planning (location and timing)

Our Aim

To identify modifiable vulnerability and recognise resilience before treatment begins — not after complications.

Our aim is not to 'geriatricise' transplant, but to introduce structured assessment of resilience **to personalise care, optimise outcomes and target support early.**

Next: Two patient stories to show CGA in action

Comprehensive Geriatric Assessment (CGA)

A multidimensional assessment of resilience and vulnerability

CGA is a **structured, multidimensional** assessment that evaluates medical, functional, psychological and social factors to **understand a patient's physiological reserve, vulnerability** and ability to tolerate intensive treatment.

Clinical Frailty Scale (CFS)

CGA brings together multiple domains to identify strengths and vulnerabilities, guide optimisation and personalise care.

Included within our CGA

- Social history
- Clinical frailty scale (CFS)
- Instrumental activities of daily living scale (IADL)
- Timed up and go (TUG)
- Mini-Cog
- Grip strength assessment
- Summary

Additional potential assessments

- Fatigue assessment
- Nutritional assessment

CGA provides a comprehensive view of the patient, moving beyond disease to inform safe, personalised treatment planning.

Case 1 – When age is misleading

35-year-old with relapsed Hodgkin lymphoma awaiting allogeneic transplant

The patient

35 years old male
Relapsed Hodgkin lymphoma
Awaiting allogeneic transplant

What changed?

CNS noticed subtle gait changes when walking into clinic

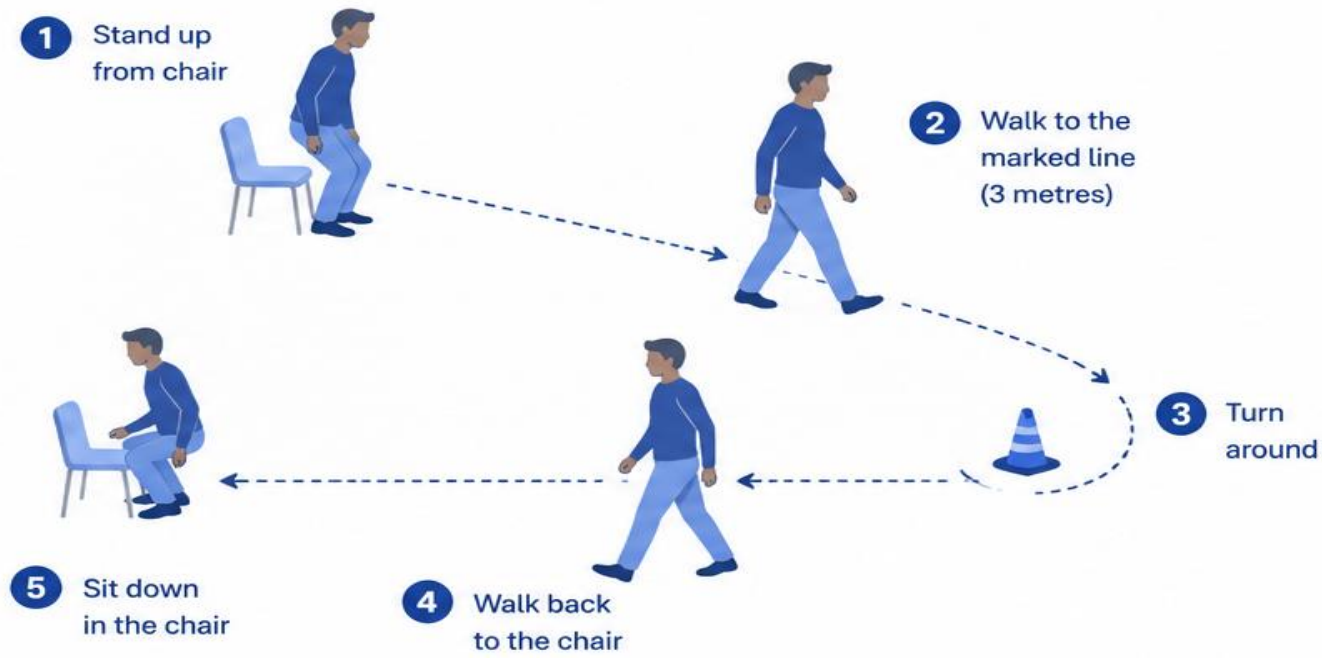
CGA findings

- Timed Up and Go >17 seconds
- Wide-based gait
- Multiple steps on turning

Action

Neurology referral
↓
Demyelinating polyneuropathy
↓
Plasma exchange (TPE) + IVIg

Timed Up and Go (TUG) >17 seconds



Abnormal gait, wide-based stance and multiple steps on turning with a prolonged TUG >17 seconds.

This was not age-related frailty.
This was treatment-related physiological vulnerability.

Case 2 – The value of a baseline

71-year-old with AML following allogeneic transplant

THE PATIENT

- 71 years old
- High-risk AML
- 9/10 donor allo transplant
- Morphological remission
- MRD negative Day +100

Appeared ‘end of the bed fit’ pre-transplant with a respectable CGA

WHAT CHANGED?

“Something didn’t feel right.”

- Slight veering while walking across the waiting room
- Urinary urgency / nocturia
- Previous inpatient fall (unwitnessed)

ASSESSMENT

- No GVHD
- Bloods normal (no anaemia, electrolytes normal)
- Neurological examination unremarkable
- On ciclosporin and pregabalin

CLINICAL CONCERN

Clinical concern despite reassuring investigations

Individually, nothing alarming.

Collectively, it didn’t sit comfortably.

↓

REPEAT CGA

This case illustrates that even when patients appear well and investigations are reassuring, **a repeat CGA can uncover early signs of vulnerability.**

Case 2 – The value of a baseline

What changed? Comparing pre-transplant with Day +100

Assessment	Pre-transplant (Day 0)		Day +100	Change
Clinical Frailty Scale (CFS)	2	→	2	No change
Grip strength	Average	→	Average	No change
Mini-Cog	5 / 5	→	5 / 5	No change
Lawton–Brody IADL *(Instrumental Activities of Daily Living)*	8 / 8	→	7 / 8	Minimal change *(-1 point)*
Timed Up and Go (TUG) *(seconds)*	**5.8 sec**	→	**9.0 sec**	**↑ 60% increase** *(3.2 seconds slower)*

Almost every domain remained stable and reassuring.
However, Timed Up and Go increased from 5.8 to 9.0 seconds –
a clear decline in functional mobility.

↑ 60%
increase in time

Still within the 'normal' range, but a clear decline in functional mobility.
This objective change reflected what we had observed clinically.

Case 2 – The value of a baseline

Why did it matter? From concern to action – preventing the next fall

1

Medication review

Review of pregabalin and other medications that may contribute to imbalance, dizziness or falls.

2

Physiotherapy referral

Targeted programme to improve strength, balance and confidence.

3

Falls risk mitigation

Environmental review, equipment, sleep-time toileting plan and safety strategies.

4

Longitudinal monitoring

Repeat CGA to follow trajectory and guide ongoing interventions.

5

Reduced risk

Proactive intervention helped prevent another unwitnessed fall.

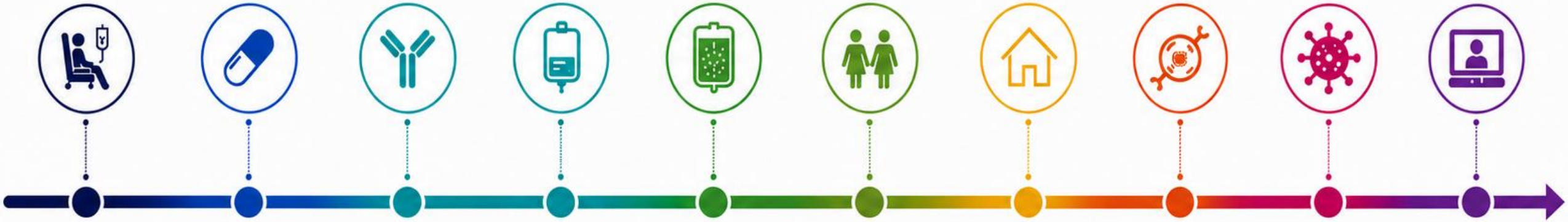
Frailty isn't binary – it changes over time.

CGA allowed us to move from reactive care after a fall to proactive intervention before the next one.

The value of CGA isn't the score. It's the trajectory.

This is why CGA should be embedded longitudinally throughout the transplant pathway – not simply performed once before treatment.

Timeline of Transformation



Pre-2000

High intensity transplants the norm

Older patients often excluded. Limited donor options. Prolonged inpatient stays.

2000s

Imatinib (Gleevec®) changes CML forever

The first targeted therapy – a new era begins.

2001

Monoclonal antibodies enter the clinic

Rituximab and others transform treatment for lymphoma and many cancers.

2010s

Reduced intensity transplants become mainstream

More patients become eligible, including older and those with co-morbidities.

2012

Cord blood transplantation grows

Another donor source increases access and flexibility.

2014

Haploidentical transplantation becomes a real option

One family member can now be the potential lifesaving donor.

2015+

Ambulatory / Outpatient transplant and chimeric antigen receptor therapy

Care moves beyond the inpatient ward – improving patient experience and outcomes.

2017

CAR T-cell therapy arrives

A revolutionary therapy for relapsed/refractory disease.

2020

The pandemic accelerates innovation

New models of care, rapid adaptation and digital innovation emerge.

2020+

Virtual clinics become embedded in care

Remote monitoring and rapid consultations improve access, convenience and continuity.

Health care is not more personalised because we know more about the disease

It is more personalised when we understand more about the person