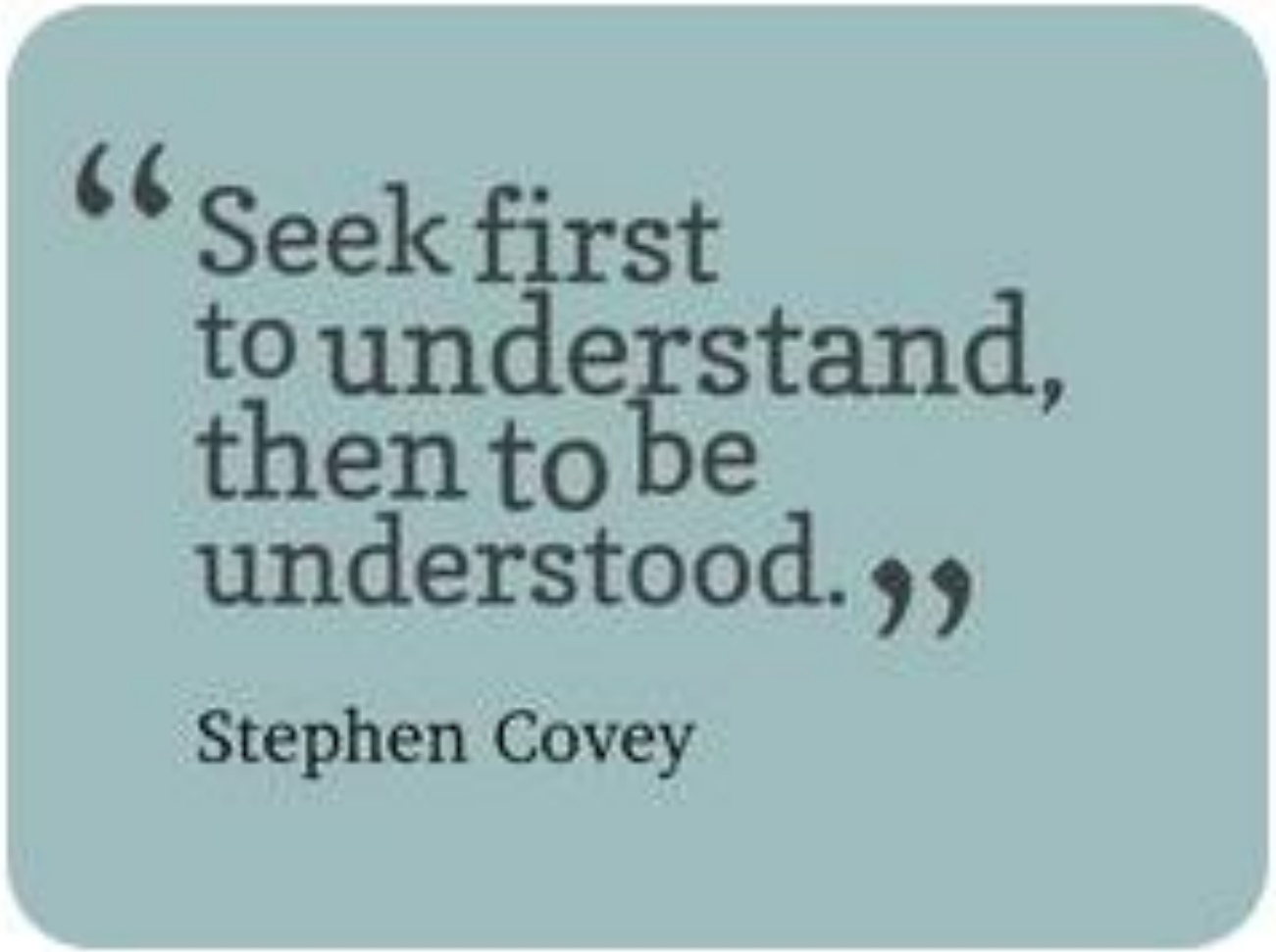
Demystifying Sickle Cell Nutrition:
What Dietitians need to know

Dr Claudine Matthews DPROF HSC RD FHEA

Sickle Cell Nutrition Webinar:

Collaboration between BDA Haematology Subgroup and BDA First Contact Dietitians

20th May 2026


“Seek first to understand, then to be understood.”
Stephen Covey

Who Am I…

South Africa

Apartheid – experienced racism, marginalisation and disempowerment

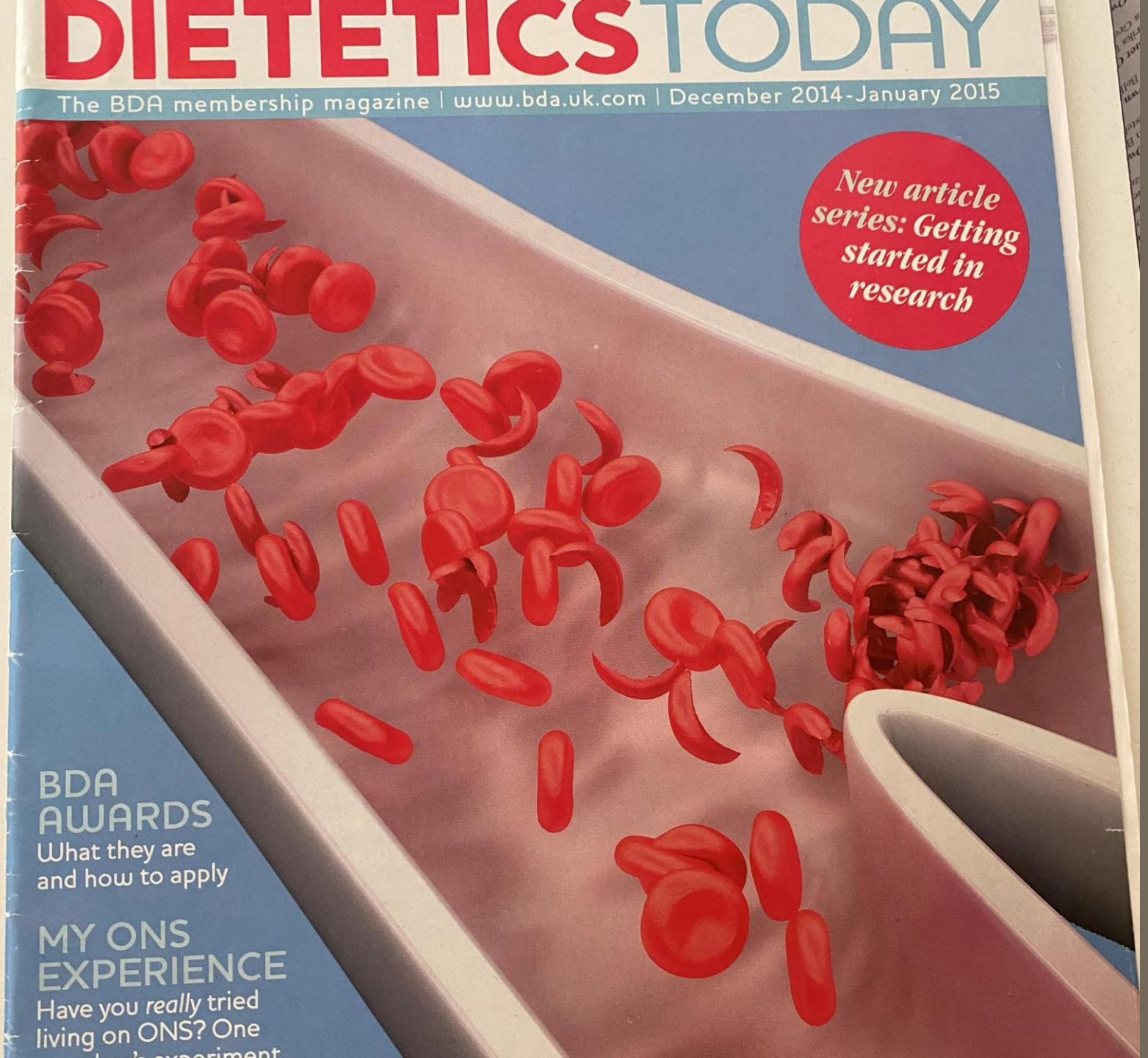
Worldview of social justice, advocacy and empowerment

Moved to the UK in 2000

Introduced to sickle cell in 2011 and sickle cell nutrition in 2014 – started professional Doctorate in 2016 completed in 2023

Founded – Sickle Cell Nutrition Academy (SCNA) - Work as Consultant Dietitian

- Leader in the field of sickle cell nutrition – guide educate others on best practices – APPG SCT, UK Forum, HCCs, Roahl Dahl Charity
- Provide expert nutritional advice and treatment for patients with complex nutritional needs – Chapter -Manual of Dietetic Practice, Guest lecturing
- Lead on innovations and research to advance policy and practice in sickle cell nutrition – NHSE funded project,
- NHS Clinical Entrepreneur 2025



Where it all started…

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The Motivation: Patient Voices

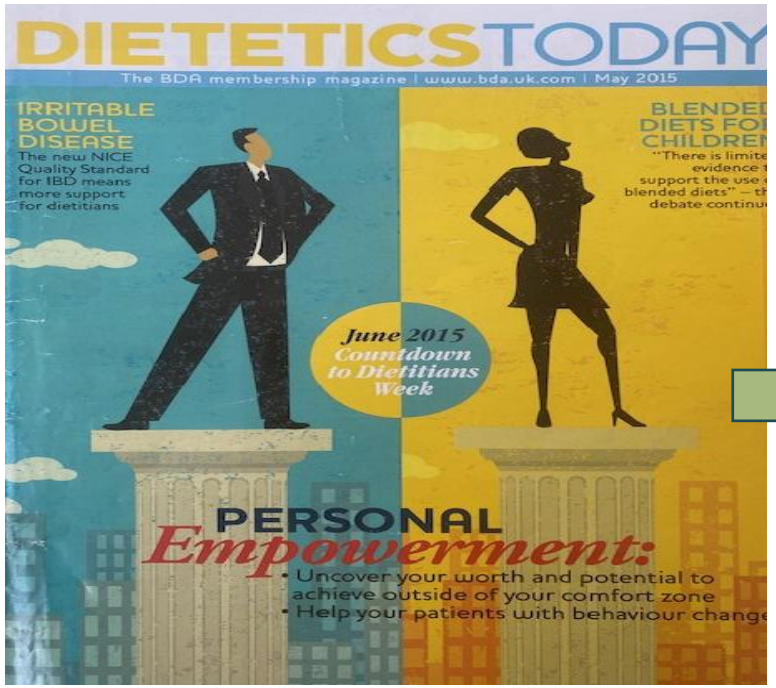
"Nutrition I think plays a major part in staying well!"

"Nutrition has been a massive part of my mental health"

"Nutrition…I think it is fundamental"

"What you are doing is so valuable. It makes us feel someone is valuing us, as this is such a key area"

"I for instance was diagnosed with osteoporosis recently and that was a bit of a shock to me and then they've now said oh yeah, we are going to start treating it now - oh well why wasn't it tracked before we got to this level…"



Becoming a Visible Force with An Audible Voice

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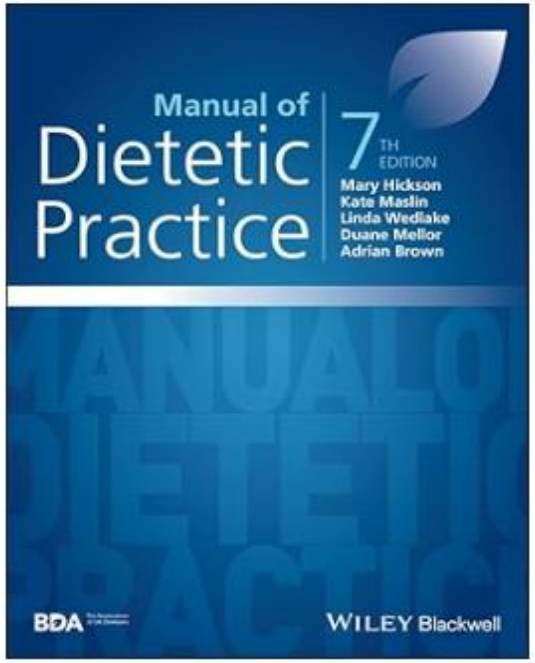

The Legacy:
Recognition of Sickle Cell Nutrition

Publication of first ever chapter on Sickle Cell Nutrition and other Heamoglobinopathies – May 2026

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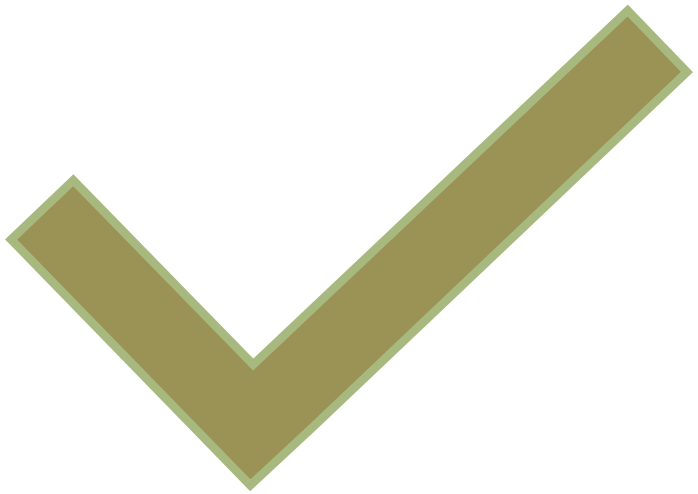
My ongoing responsibility…



EQUIP	EQUIP – You with sickle cell specific nutritional knowledge
EMPOWER	EMPOWER – You to provide tailored dietetic care
INSPIRE	INSPIRE – You to be more curious and extend your involvement in research and advocacy

Introduction to Sickle Cell Disease

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Introduction to Sickle Cell Disease (SCD)

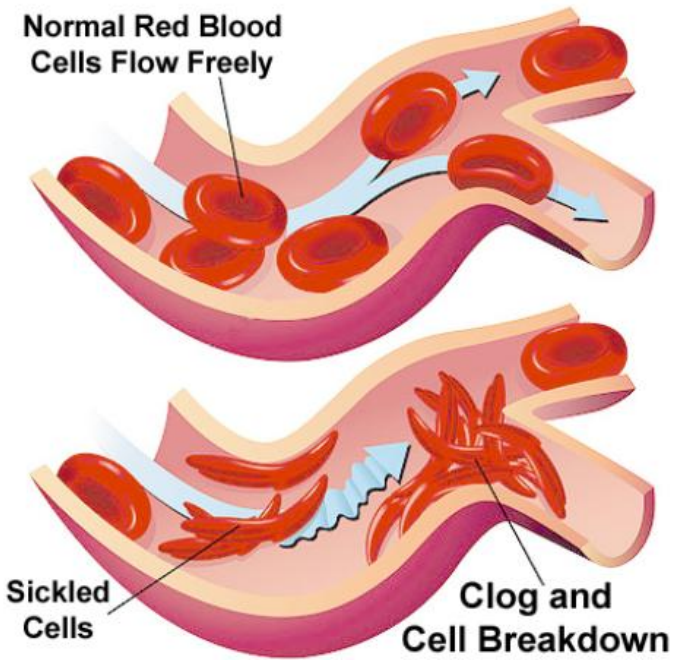
WHAT IS SICKLE CELL?

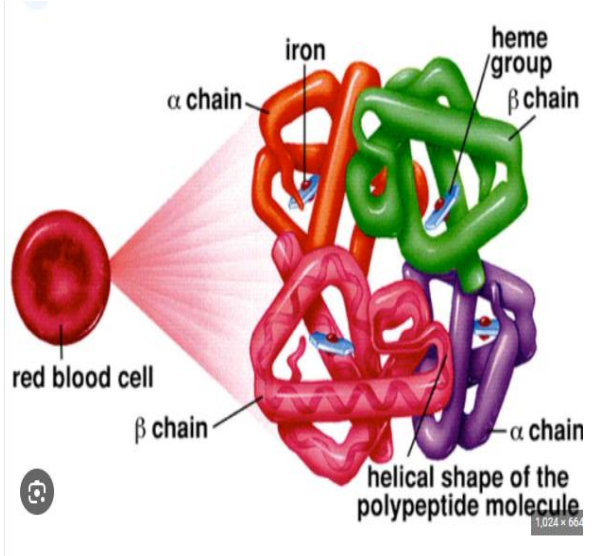
- It is an inherited disorder
- It affects the red blood cells
- It affects the haemoglobin (Hb) in red blood cells
- Affects Haemoglobin component of red blood cells
- Genetic defect results from the substitution of one of the amino acid sequences in the globin chain – causes unstable (HbS)

IMPACT OF SCD?

- Sickle Cell Disease associated with high levels of
  - Morbidity
  - Mortality
  - Disability
  - Poor Quality of Life
  - [1](National Confidential Enquiry into Patient Outcomes and Deaths - NCEPOD, 2008):
- [2,3]Global public health problem (WHO, 2006, UN, 2008)

[1]National Confidential Enquiry into Patient Outcomes and Deaths - NCEPOD, 2008





Blood Flow in SCD?

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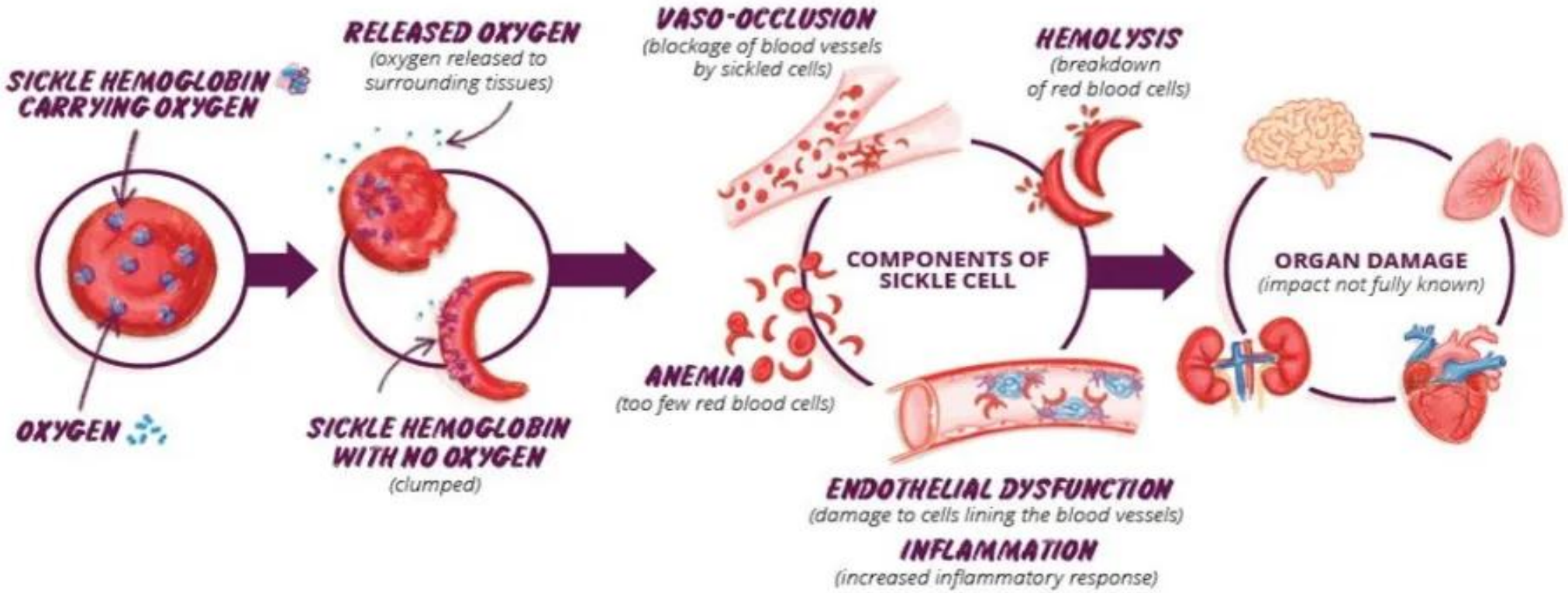
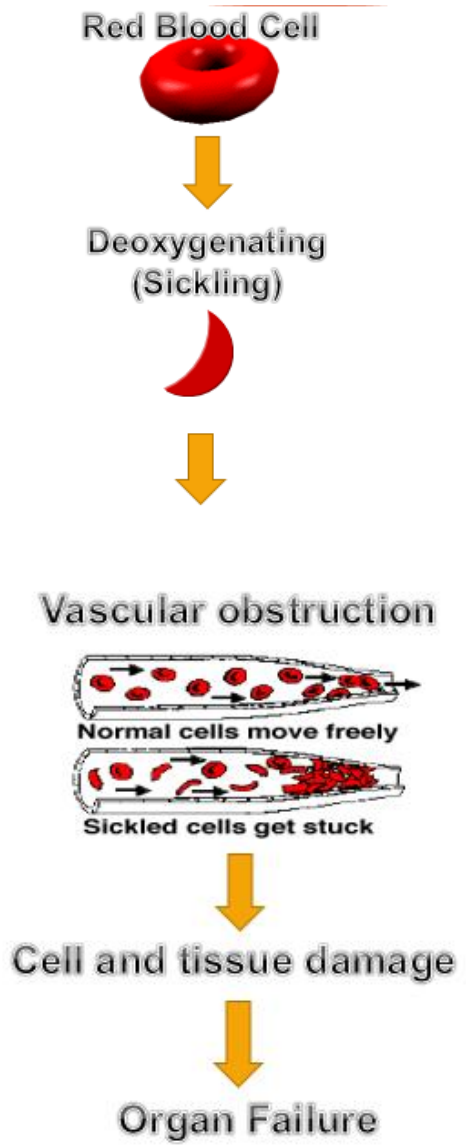
PROCESS OF SICKLING

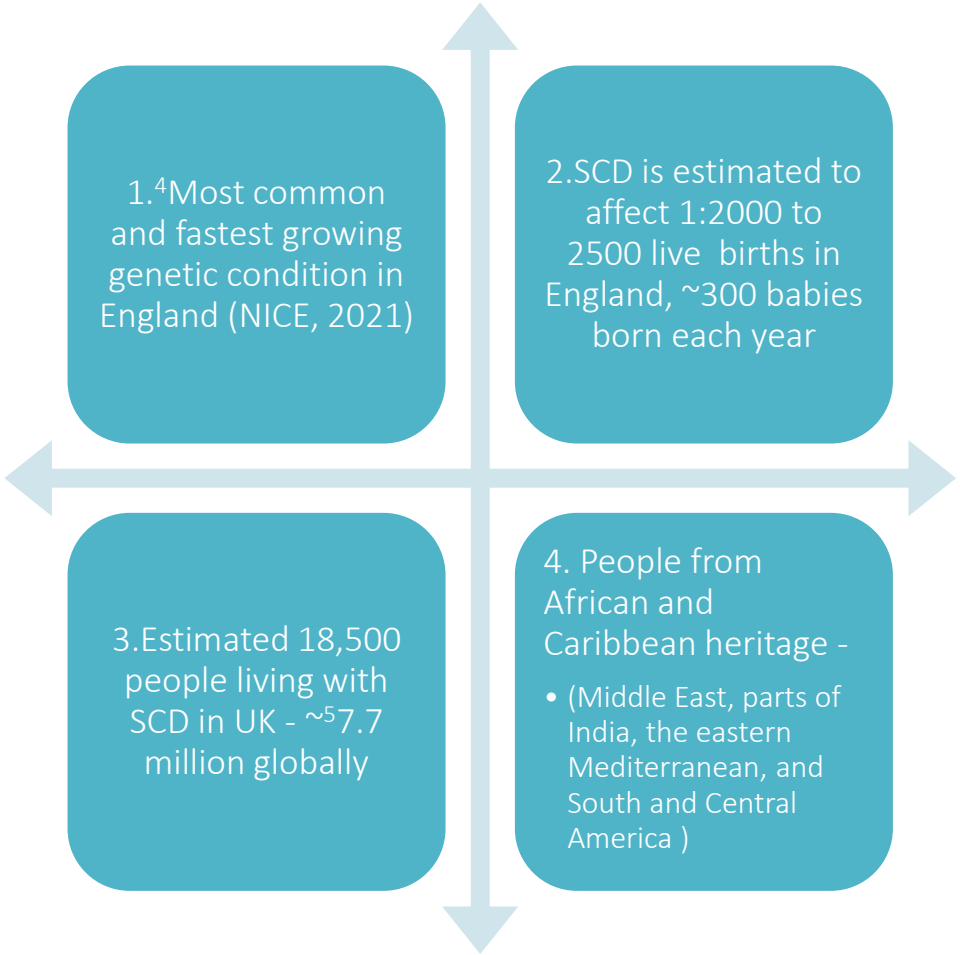


(www.sicklecellspeaks.com, n.d.)

The Sickling Process



Epidemiology and Prevalence



Types of SCD:

There are three most common types of Sickle Cell Disease:

1. Haemoglobin SS (HbSS)
2. Haemoglobin SC (HbSC)
3. Sickle Beta Thalassaemia (Hb SBThal)

However, there are around 1000 variants of haemoglobin creating other SCD, e.g. SE, SD, SN, SK

Personal critical reflections to consider in sickle cell nutrition:

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‘Begin with Why?’

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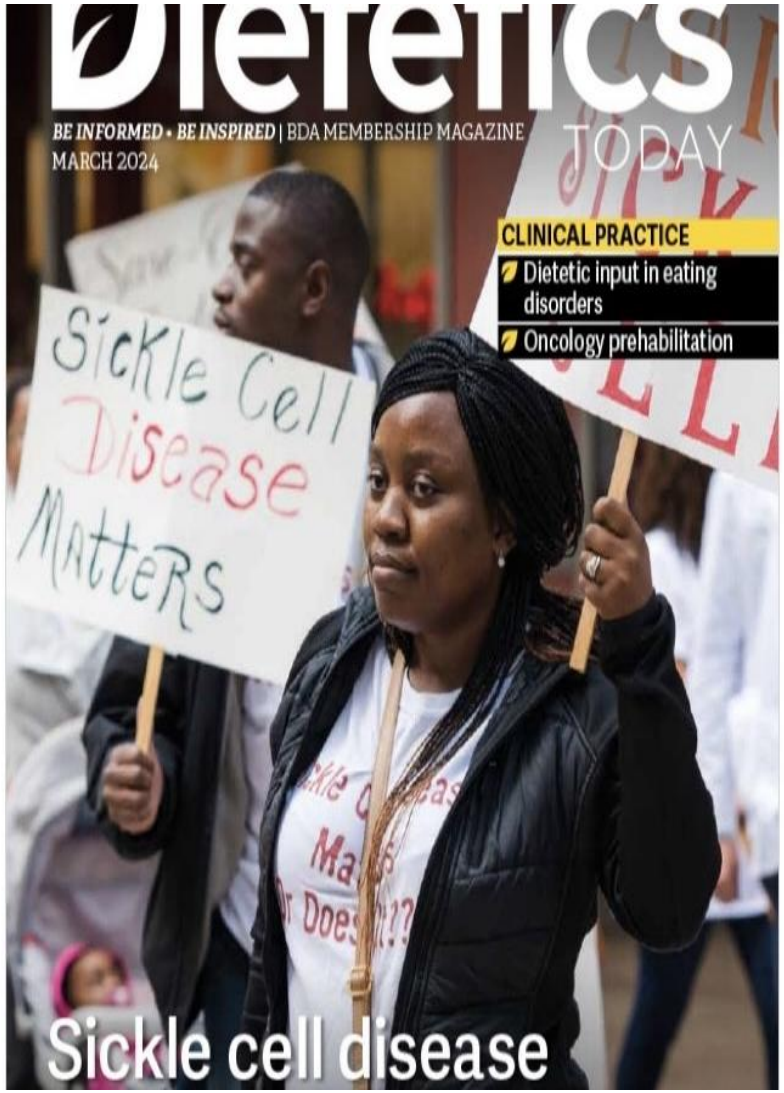
‘Break the Cycle’

The lack of nutrition service provision:

- Marginalisation
- Invisibility
- Health inequality

Affecting patients,

- Experience
- Access
- Outcomes



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‘Need for Innovation’

Sickle Cell Nutrition Academy (SCNA)

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‘Close the Critical Gaps’

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Gaps in the Literature

01

Marginalisation of SCD/patients not considered

02

[6]Term Disease -related - malnutrition not applied to sickle cell nutrition research

03

[7]No research on the nutritional management of SCD

04

[7]Clear calls for nutrition to be integrated into/become part of standard care provision

[6]Matthews, C.E., 2019. The role of nutritional care in Sickle Cell Disease: A real phenomenon. ACTA Scientific Nutritional Health, 3 (2), pp.74-80.
[7]Matthews C. Co-developing a health literacy framework to integrate nutrition into standard care in SCD, Doctoral thesis, 2023.

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What do you need to know!

Consider the Marginalisation of Sickle Cell Nutrition

On Monday 15th November, 2021, the All-Party Parliamentary Group on Sickle Cell and Thalassaemia (SCTAPPG) published the report 'No Ones Listening'. This report came after an inquiry into avoidable deaths and failures of care for those with affected by sickle cell.

Focusses on the Medical Management

[7]Qualitative participatory study

- Sickle cell service users/carers and service providers
- Findings correlated closely with the No one's listening Report

Nutrition is marginalised

- lack of priority given to nutrition and its not important enough to treat

Nutrition is invisible

- Importance of nutrition is overlooked

Nutrition is a health inequality

- Affects patients experience, access and outcomes of nutrition

Lack of nutrition education, training and resources

Lack of research on nutritional management

‘Nutrition is Fundamental’

Cause	Impact	Management
• Chronic haemolysis: Ongoing break down of your red blood cells • Vaso-occlusion: • Sickle cell crisis causes tissue and organ damage • Impaired Immunity: • Increased risk of infection	• Low oxygen levels in the blood • Vitamin and mineral deficiencies • Chronic anaemia and fatigue + appetite suppression • Impaired immunity • Chronic Inflammation	• Optimisation of nutritional deficiencies • Regular screening for malnutrition risks • Preventing end organ damage • Optimisation of immune function

Nutritional Implication in SCD

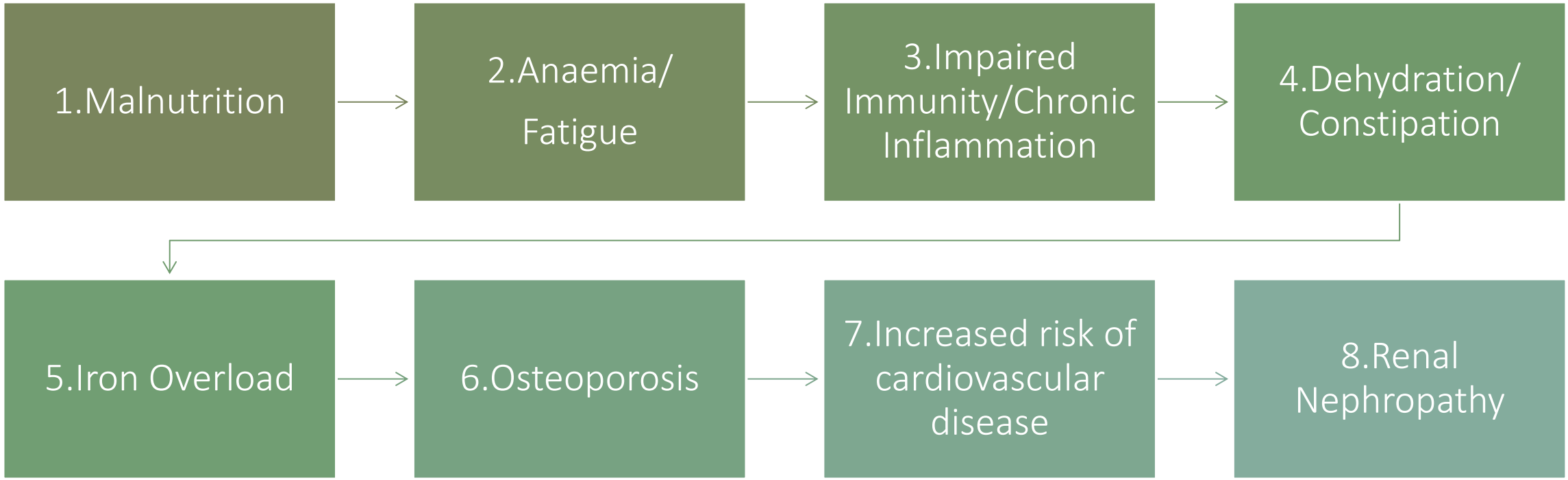
NUTRITIONAL RISKS

- SCD - **complex nutritional problems** and **complications**
  - **Wastage of nutritional resources**
  - **due to ineffective red cell production**
  - **Impacts growth and development**
- SCD - **multi organ** and **multi -system involvement**
- Sickle cell related complications:
- Including renal failure, liver failure requiring liver transplantation, cardiac failure due to cardiac iron overload and chronic lung disease.
- **Chronic Inflammation:**
  - Production of free radicals
  - Caused by iron overload
  - Infections,
  - Tissue damage

NUTRIENT DEFICIENCIES

- [9]Malnutrition risks
  - High Resting Energy Expenditure (REE)
  - High protein turnover
  - High red blood cell turnover
  - Need for more tailored research
- Macro Nutrients:
  - Hypermetabolism – increased Energy (Carbohydrates and Fats)
  - Increased Protein
  - Increased fluid
- Micronutrients:
  - Zn, Se, Vit D, A, C, E, B vitamins, folic acid
  - Iron – (absence of iron overload)
  - Omega 3 Fatty acids

[9]Hyacinth, H.I., Gee, B.E. and Hibbert, J.M., 2010. The role of Nutrition in Sickle Cell Disease. *Nutrition Metabolic Insights,* [pdf] 3, pp. 57-67.



Common Nutritional problems

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Table One: Main Clinical Manifestation of affected Organs and Systems[a]

System/Organ	Clinical Manifestation/Complication
Skeletal	Osteonecrosis, Osteomyelitis, leg ulcers, avascular necrosis
Genitourinary	Chronic renal insufficiency, priapism, chronic renal failure
Gastrointestinal	Cholelithiasis, viral hepatitis from transfusion, liver failure
Spleen	Splenic enlargement and fibrosis, acute aplastic anaemia, parvovirus B19, functional asplenia, leucocytosis
Hepatobiliary	Indirect hyperbilirubinemia
Caridiopulmonary	Pulmonary hypertension, cardiomegaly, cardiac failure
Central nervous	Stroke, silent infarcts

[10]Sickle cell related nutritional risks

[10]Matthews, C., 2015/16. *Nutritional implications of sickle cell disease. Complete Nutrition (CN) Magazine*, 15 (6), pp. 46-48.

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‘Socio-ecological Nutritional Challenges’

[7]Socio -Ecological Factors affecting nutrition

(Matthews, 2023)

Micro – level factors :

Personal and Interpersonal

Personal: Internal factors

Psychological, emotional, attitudes, beliefs, culture, stigma, religion, health symptomology

Personal: External factors

Environment, time, knowledge, family, culture, food traditions, peer support

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Nutrition Across the Life course

Paediatrics

- Delayed growth
- Stunting
- Wasting
- Fussy eating
- Failure to thrive
- Disease related malnutrition

Adolescents

- Delayed Puberty
- Infection risk
- Nutrient Deficiency
- Disease related malnutrition

Adults and Ageing

- Increased morbidity and mortality
- Pregnancy
- Frailty
- Gastrointestinal problems (side effects of meds)

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‘Opportunity for Research’

Sickle Cell and Nutrition:

Sickle Cell And Nutrition Experience Research (SCANER) Study

Sponsored by Sheffield Teaching Hospital (STH) and NE&Y Heamoglobinopathy Coordinating Center (HCC)

Subsets – Adults living with SCD, Caregivers/parents of children with SCD and Providers of SCD Care

What do we need to manage sickle cell nutrition!

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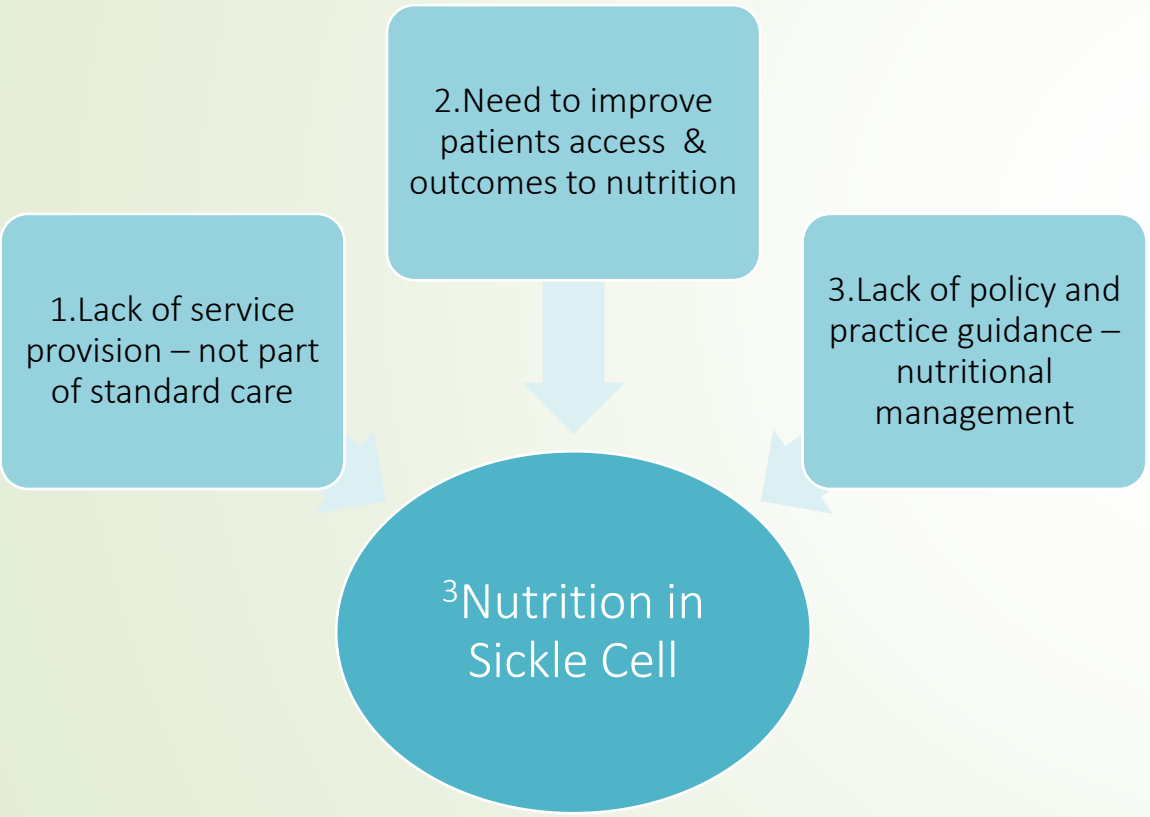
Understand 'the problem'



[11]Nutrition Standard 1	• Dietitians to be part of SCD MDT
Nutrition Standard 2	• Patients to be screened for malnutrition
Nutrition Standard 3	• Sickle Cell patients at risk or malnourished need to be treated

[11]Sickle Cell Society (2018). Standards for the Clinical care of adults with sickle cell disease in the UK.

Sickle cell and other haemoglobinopathies

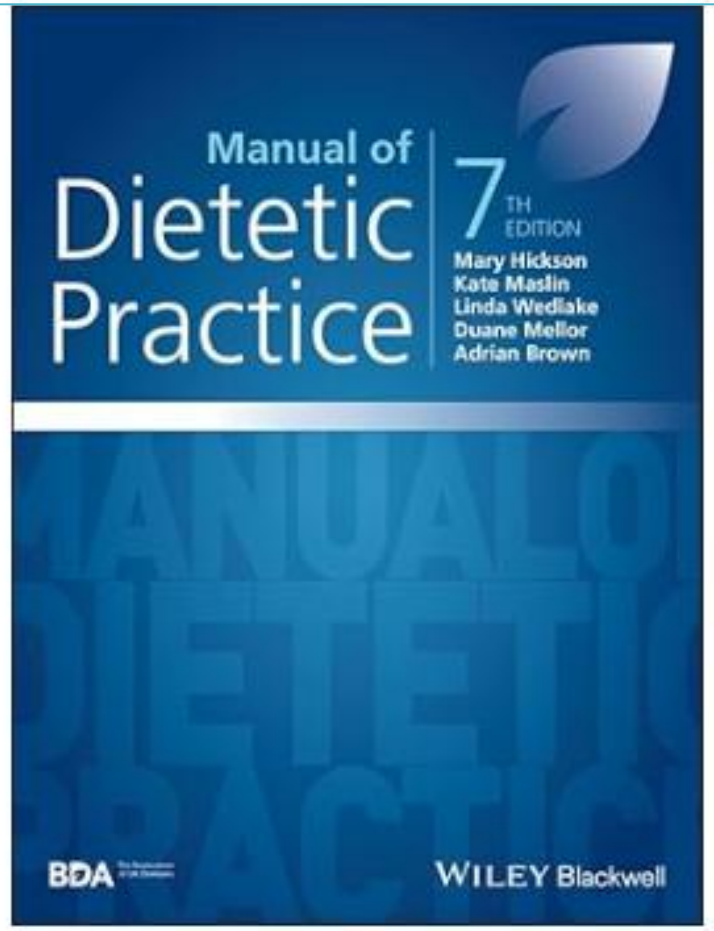
Claudine Matthews DProf RD

Consultant Dietitian in Health and Social Care, Winner of the BDA (GET) Dame Barbara Clayton Award 2024, Shoreditch Park and City Primary Care Network, London, N12 8QJ, UK

Key points

Aspect of care process	Key points relevant to this area of practice
Brief introduction	■ Haemoglobinopathies are genetically inherited red blood cell disorders, with wide-ranging nutritional implications related to the clinical features and treatment modalities of the respective conditions.
Assessment	■ Nutritional assessment is multi-factorial to address common and specific nutritional features such as chronic anaemia and fatigue, increased red cell turnover, oxidative stress, appetite suppression and the effects of multi-organ and system involvement.
Diagnosis	■ Nutrition and dietetic diagnosis (NDD) may relate to nutritional problems linked to the clinical features and complications of the disorder, frequency of hospital admission and side effects of treatment modalities.
Intervention	■ Paucity of research on the nutritional management of haemoglobinopathies has resulted in a lack of nutrition guidance, policies and nutrition service provision. ■ Nutritional interventions should be tailored to address the unique nutritional needs, risks, challenges and influencing factors/barriers of the respective haemoglobinopathies.
Implementation	■ The nutritional management aims to reduce the morbidity and poor quality of life outcomes associated with haemoglobinopathies linked to the clinical features and symptomology of the individual patients, predominantly painful episodes and haemolysis in sickle cell disease (SCD) and effects of iron overloading in thalassaemia.
Monitor and review	■ As service provision is variable in both disorders, the focus of the monitoring and review is influenced by the level of service provision provided – this will include assessment, NDD, goals, outcomes and intervention actions.
Evaluation	■ Evaluation is impacted by the level of service provision and may include improvement in weight changes, nutrient optimisation in deficiency and appetite suppression, improvement in nutritional symptomology and functionality.

Influence ‘Policy and Practice ’



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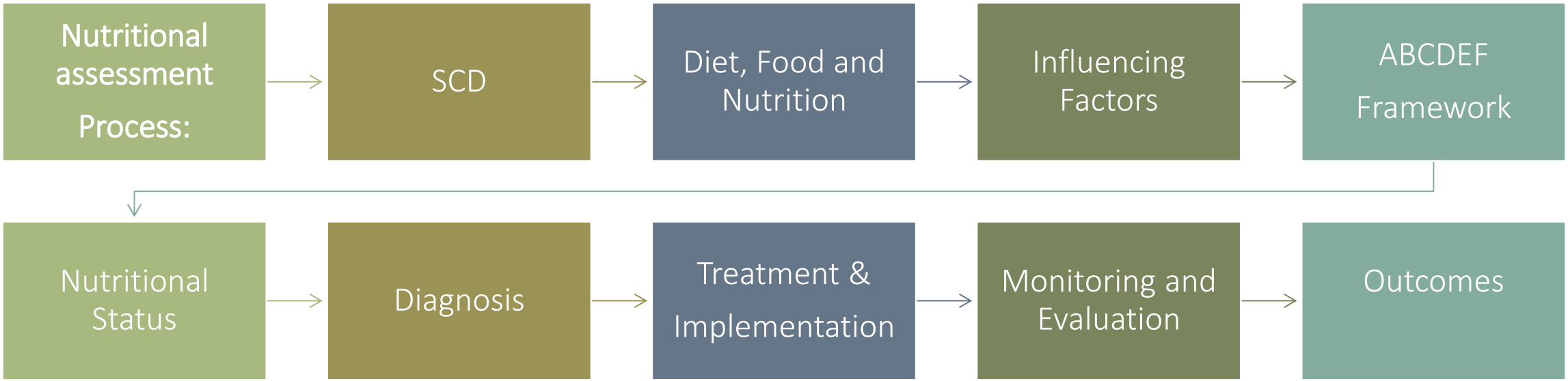
Apply the Comprehensive Dietetic Care process



Factors to consider in nutritional assessment: insights from a specialist sickle cell dietitian

Comprehensive assessment of clinical status – works alongside pharmacist and physio therapist

Review recent biochemistry

Reviews medication

Mobility

Recent complications or treatments

Explore GIT side effects from opioids, hydroxyurea treatment, transfusion history, leg ulcers,

Sleep patterns, fatigue

Recurrent infections or hospital admissions – monitor appetite and eating patterns

Assessing overall nutrient intake

Monitoring anthropometry – weight, height, BMI, handgrip strength, sit to stand test

Renal impairment can be an issue – due to proteinuria

Assess micronutrient status – folate, zinc, Vitamin D, Iron (iron overloading)

Monitor hydration – to prevent crisis

Pica in children (eating non-food items like paper, sand, soil) – refer to psychology for support

Monitor and manage delayed growth and puberty

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Close the Assessment Gaps

Malnutrition Universal Screening tool (MUST) – BAPEN

BMI

Weight loss

Acute disease factor (oral intake over the last 5 days)

NEW Malnutrition Diagnostic Tool – ESPEN

[12]Global Leadership In Malnutrition (GLIM)– Diagnostic Tool

BMI, weight loss, Inflammation, Disease Burden, Calf circumference

12 Cederholm et al. GLIM criteria for the diagnosis of malnutrition – A consensus report from the global clinical nutrition community, Clinical Nutrition, 2019, Volume 38, Issue 1,

‘Opportunity for Industry Collaboration

Collaborating with Abbott Nutrition

Supported by a medical liaison officer

Undertaking Service Evaluations to identify the prevalence, management and cost of malnutrition in SCD

2 Areas:

Cambridge

Southeast London

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Support Student Placements:
SCNA: D-Placement Pre Reg Masters Student Dietitians

2 Projects:

1. Survey to evaluate the Sickle Cell Nutrition Eatwell Guide – how its being used in practice – 2025

2. Conduct a literature search on the role of nutrition in SCD over the last 20 years - 2026

3. Contribute to the development of nutritional leaflets in SCD to close the resources gaps

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What do we need to change to improve sickle cell nutrition!

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3 Key health shifts – NHS Health Plan

- Sickness to treatment prevention
- Hospital to community
- Analogue to digital

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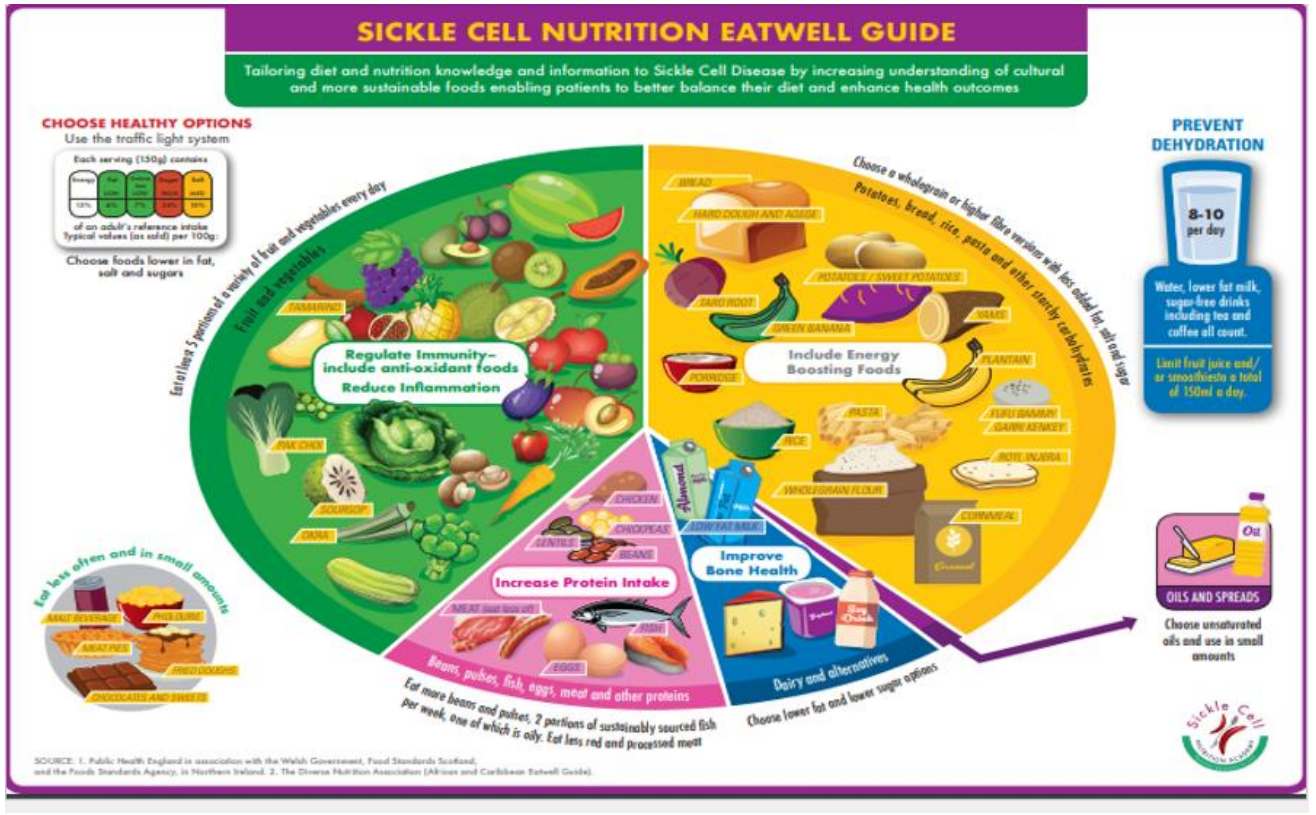
‘Build Tailored Solutions’

7 Key Nutrition Principles in Sickle Cell

1. Choose Healthy options
2. Prevent Dehydration
3. Regulate Immunity
4. Reduce Inflammation
5. Include energy boosting foods
6. Increase protein intake
7. Improve bone health



WHAT IS SICKLE CELL DISEASE?

Sickle cell disease is a genetically inherited red blood cell disorder and manifests in both clinical and nutritional features. The main clinical features of SCD (see table below), are directly responsible for the main nutritional features and related problems in SCD. Thus, the **Sickle Cell Nutrition – EAT WELL GUIDE** is a visual and practical resource, tailored to the specific nutritional needs and risks of sickle cell patients to improve their health outcomes and quality of LIFE.

CHRONIC HEAMOLYSIS

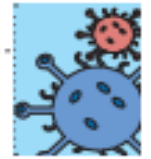
Rapid breadown of red blood cells under low oxygen conditions

VASO OCCLUSION

Blockage of small and large blood vessels with sickle shaped blood cells

IMPAIRED IMMUNITY

Impaired functioning of the spleen leading to increased risk of infection



WHY? Effect of Clinical features	• Chronic anaemia and fatigue, increased red blood cell turnover, low oxygen levels in the blood, increased oxidative stress leading to chronic inflammation	• Reduced or obstruction of blood flow in blood vessels, leading to tissue or organ damage and chronic inflammation	• An increased risk of infection, increased nutritional requirements and chronic inflammation
HOW? Optimise your dietary choices	1. CHOOSE HEALTHY OPTIONS 2. PREVENT DEHYDRATION 3. REGULATE IMMUNITY INCLUDE ANTI-OXIDANTS 4. REDUCE INFLAMMATION 5. INCREASE ENERGY BOOSTING FOODS 6. INCREASE PROTEIN INTAKE 7. IMPROVE BONE HEALTH	Legend	To improve your overall health and prevent diet related disease To reduce the effect of dehydration as a trigger for sickle cell crisis To reduce your risk of infection and choose foods high in Vitamin A, C, E To prevent cell damage and choose foods rich in omega 3 fatty acids To manage the effects of chronic anaemia, tiredness and fatigue To build and repair the body's cells, tissues and red blood cells To prevent osteoporosis by boosting your daily intake of calcium and Vitamin D intake
HOW? Optimise your diet when unwell	**Energy and Nutrient dense foods:** (foods providing large amounts of energy in small amounts) – cultural • Avocado dips, creamy dips, hummous and bread, • Crackers and cheese, cheese on toast, peanut butter/nut butters on toast • Thick creamy yogurts or soya alternatives, • Dried fruit, unsalted nuts/seeds, rich fruit smoothies • Energy supplements like, nourishment, Complan, Build up shake/soups		**Suggestions for food fortification:** (Adding ingredients that you may have at home to foods/drinks to increase the nutrient content) **Food fortifiers:** cheese, butter, peanut butter, ice cream, cream, (honey, sugar, jam) * Choose full fat versions of foods/drinks Avoid low fat foods/drinks

*If you are diabetic – ensure to adjust your medication accordingly

YELLOW FOOD GROUP – Energy Boosting Foods
GREEN FOOD GROUP – Anti-Oxidant Foods
PINK FOOD GROUP – Protein Rich Foods
BLUE FOOD GROUP – Protein Rich Foods
PURPLE FOOD GROUP – Energy boosting foods

For more related resources – www.sicklecellnutritionacademy.com

Sickle Cell Nutrition Academy

Incorporate Digital solutions:

'Food as Medicine Video Education Series' – NE&Y HCC

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Deliver Blended community-based Specialist Nutrition Programmes – SWL ICB + West London HCC

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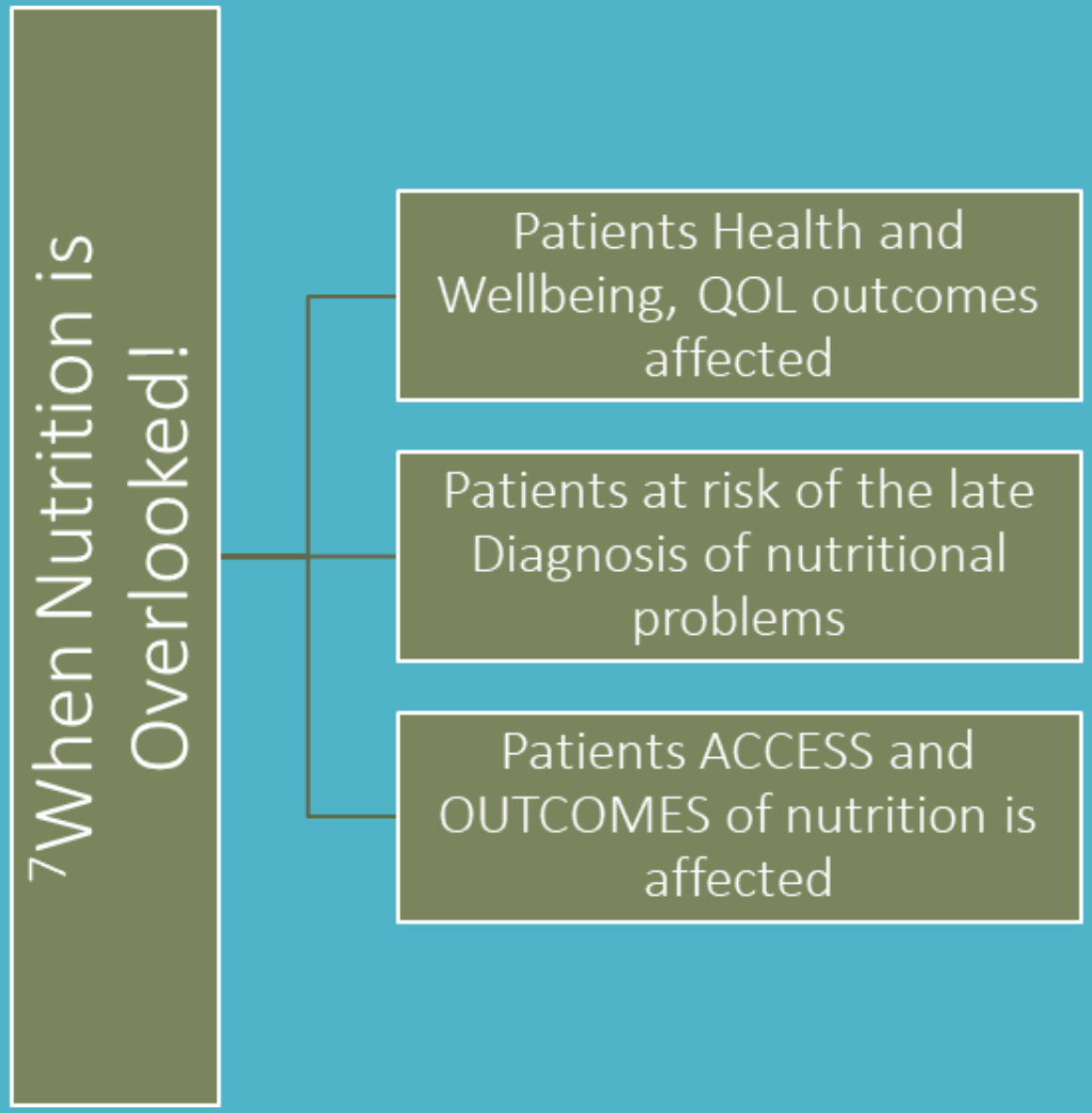

'Address the Invisibility'

The Annual Advancing Sickle Cell Nutrition Conference

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Remember: Nutrition in Sickle cell is more than PAIN!

- Growth delays, delayed puberty
- Multi-organ system failure
- Organ damage, leg ulcers
- Avascular necrosis of hips/shoulders
- Stroke
- Pulmonary hypertension
- Acute chest syndrome
- Renal Nephropathy
- Gallstones – Cholecystectomies
- Gastrointestinal problems – side effects of medication and treatment modalities (constipation, nausea, vomiting)
- Need for more tailored Nutritional research

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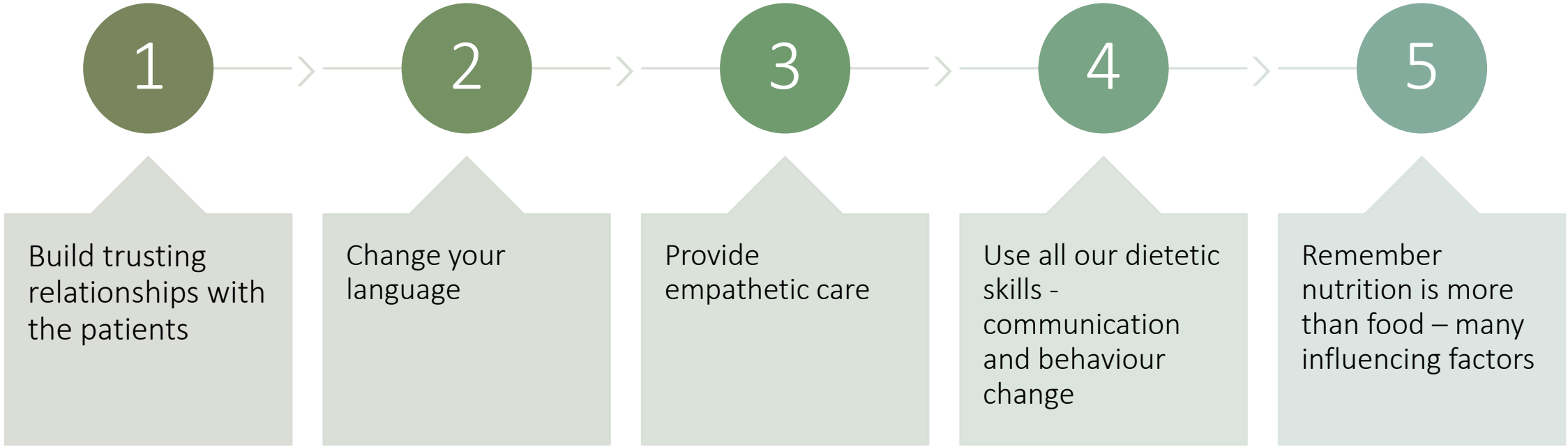
Not a one size fits all solution



Critical nuances in sickle cell nutrition service planning and delivery

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Improve or increase your visibility in the SCD MDT

Its not a one size fits all approach – consider the marginalisation of the patient population

Consider a whole person's approach to nutritional management

Remember: sickle cell is more than pain

There are many sickle cell related complications with nutritional risks and challenges

Important to empower your patients

Critical nuances in sickle cell nutrition service planning and delivery

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INNOVATION FOR CHANGE

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Recommendations: Our Call to Action

- Include clear and specific nutritional management standards in the UKFHD Quality standards
- Include these specific nutrition standards in The West Midlands Quality Standards Peer Review Service
- Implement the National Nutrition Standards – into existing referral policies and guidance
- Nutritional management to be encouraged and supported by the HCC's, SHT, LHT, National Heamoglobinopathy Panel
- Dieticians to be part of the SCD MDT, with Dietetic assessment part of the patient's annual review

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Thank you!

With Acknowledgement to the BDA Oncology Group, Haematology subgroup and First Contact Dietitians Group

QR Code for HCP Link: SWL Nutrition Programme

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