Sickle Cell Nutrition:
Dietetic Management Considerations in Patient Care Provision

Presented by

Dr Claudine Matthews DPROF HSC RD FHEA

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Presentation Overview

Part One	1. Rationale, Aetiology, Clinical features and Nutritional implications in SCD
Part Two	2.Context and Considerations for the Nutritional Management in SCD
Part Three & Four	3.Recommendations: Our Call to Action 4. Introduction to the NHSE Nutrition Resources and Information

Part One:

1.Rationale, Aetiology, Clinical Features and Nutritional Implications in SCD

Rationale for Sickle Cell Nutrition

‘Why Nutrition in SCD matters’

It is about **patient safety, patient experience and improving QOL outcomes** for the patients

NHS Outcomes Framework

Domain 2 – improving QOL for LTC’s
Domain 4 – improving patient experience

Public Health Outcomes Framework

Life expectancy
Healthy life expectancy
Reducing Health inequalities
Improving the health status and health outcomes

Aetiology of Sickle Cell Nutrition

Clinical Features of SCD → Growth delays, nutrient deficiencies, [2]malnutrition risks

[3]Nutrition overlooked, under-developed and not part of standard care in SCD

1. United Nations (UN). Recognition of sickle cell disease as a public health problem, 2008. [online].
2. Obeagu EI, Obeagu GU. Malnutrition in sickle cell anemia: Prevalence, impact, and interventions: A Review. Medicine (Baltimore). 2024 May 17;103(20) e38164
3. Matthews C. Co-developing a health literacy framework to integrate nutrition into standard care in SCD, Doctoral thesis, 2023.

Clinical Features linked to Sickle Cell Nutrition

 Chronic Haemolysis – rapid break down of red blood cells	Chronic anaemia/fatigue, increased red cell turnover, increased cardiac demand/expenditure, increased oxidative stress, chronic inflammation
 Vaso-occlusion – blockage of large and small blood vessels	Ischaemia and infarction in blood vessels causing tissue damage, organ damage and chronic inflammation
 Impaired immunity – impaired functioning of the spleen	Increased risk of infection and increased risk of malnutrition due to increased nutritional requirements

Nutritional Implications and Complexity of Sickle Cell Nutrition

Nutritional Features/Risks

- **The basis of the increased risk of malnutrition in SCD**
  - High Resting Energy Expenditure (REE),
  - High protein and red blood cell turnover
  - Impaired immunity
  - Low Body Mass index (BMI),
  - Increased oxidative stress and chronic inflammation
  - Appetite suppression
- **Multiple Influencing Factors**
  - Micro, Meso and Macro level Influencing Socio-ecological factors affecting nutrition
  - Including psychological and social factors

Nutrient Requirements

- **Paucity of research on the nutritional management in SCD**
- **Macro Nutrient Considerations:**
  - Energy – (factor in disease related factors)
  - Protein
  - Fluid (increased requirements)
- **Micronutrient Considerations:**
  - Zn, Se, Vit D, A, C, E, B vitamins, folic acid
  - Iron – (absence of iron overload)
  - Omega 3 Fatty acids

Common Nutritional Problems:

Malnutrition, chronic anaemia/fatigue, increased risk of infection, constipation, dehydration, osteoporosis, pica, iron overloading

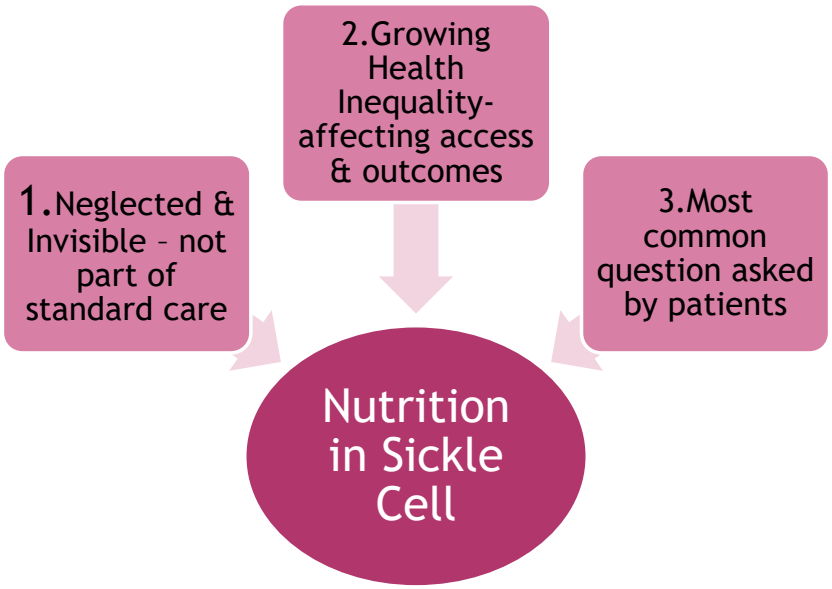
Multiple Influencing Factors

Table 2: Socio-ecological factors affecting nutrition and service provision	
Micro-level	Personal internal factors: Psychological, emotional, attitudes, beliefs, culture, stigma, religion, health symptomology Personal external factors: Environment, time, knowledge, family, culture, food traditions, peer support
Meso – Level	Meeting unmet nutrition needs of patients Lack of nutrition service provision Lack of education, training and resources in nutrition in SCD
Macro-level	Structural social factors: Ethnicity, race, social class, deprivation, poverty, education

Part Two:

2.Context and Considerations for Nutritional Management in SCD

Context for Nutritional Management in SCD



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

Dietetic Management Processes

Current Dietetic Management in SCD

Acute

(With local funding agreements)

MUST screening

Patient admitted with a crisis

Drowsy, with poor appetite

S/B haematology dietitian

No follow up in place

Dieticians Not part of MDT

Dependent on local funding agreements

Limited dietetic input

Primary Care

(Unsure of Dietetic input)

Unsure of MUST Screening

Patient referral and Engagement

Level of Nutrition Service provision

Unsure of any Funding Agreements

Reduced awareness

Limited dietetic input

Impact of limited nutrition service provision

Limited Nutritional Assessment and Follow up Patients have – Self-Research, Self-Diagnose and Self-Manage their complex nutritional needs

Growing Health Inequality:

Impacting patients, Experience, Access and Outcomes of nutrition

Urgent Action in Needed!

What the patients and providers have said!

SU-C (10) – "in general there needs to be a bigger conversation from initial doctors to consultants…the biggest like nutritional conversation I've ever had with any of my doctors was you need to drink more water…'there needs to be a bigger conversation because that would have been a lot more beneficial'…when we have done like private research".

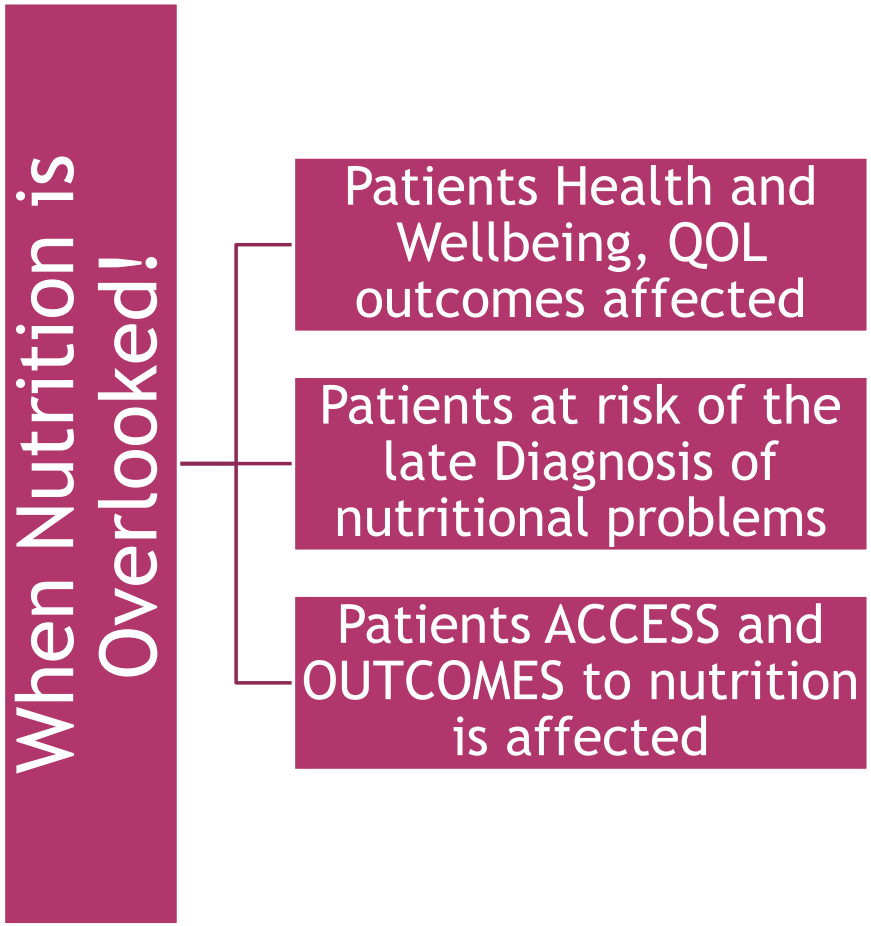
SU-C (6) – "The conversation needs to happen earlier, and continue to happen, so the reinforcement of the message of good health and nutrition, just as they reinforce you must take your folic acid and you must take your penicillin, it should be reinforced that you should be eating".

SU-C (2)- "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…".

SP (2)- "because we got a new consultant at the moment, we are getting more and more referrals because she seems to be quite nutrition pro, so I'm starting to learn a little more about it on a day-to-day basis".

Part Three:

3. Recommendations:
Our Call to Action


When Nutrition is Overlooked!
Patients Health and Wellbeing, QOL outcomes affected
Patients at risk of the late Diagnosis of nutritional problems
Patients ACCESS and OUTCOMES to nutrition is affected

Evidence to support Policy and Practice Change!

Themes

Theme 1-Invisibility of SCD

Theme 2-Under recognition of the importance of Nutrition

Theme 3 – Lack of priority to Nutrition

Theme 4 – Multiple Factors affecting nutrition and service provision

Knowledge and Care Gaps

1. Reflects level and quality of nutrition service provision
2. How it Impacts patient's experience, access and outcomes of nutrition
3. Highlights the need for more nutrition service provision
4. Requires a comprehensive approach to policy and practice guidance
5. Developed a Novel PEECE Outcomes based Model

Whole systems Strategy

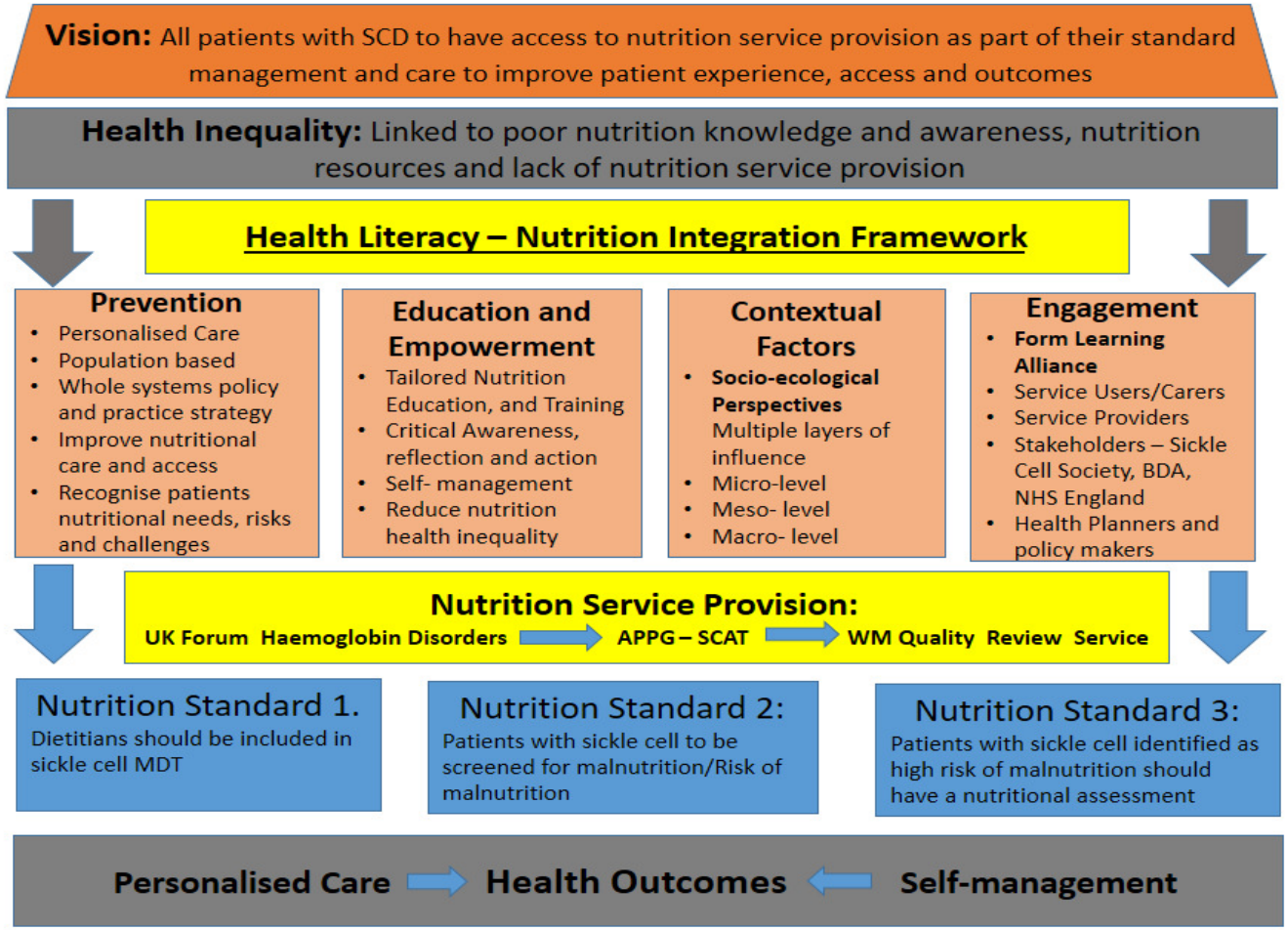
1. Need a Health Delivery outcomes-based strategy tailored to sickle cell nutrition

2 To improve patients access and outcomes to nutrition

3. To address the under-recognition and lack of priority to nutrition
4. To support the development of nutrition service provision and tailored nutrition policy and practice guidance in SCD

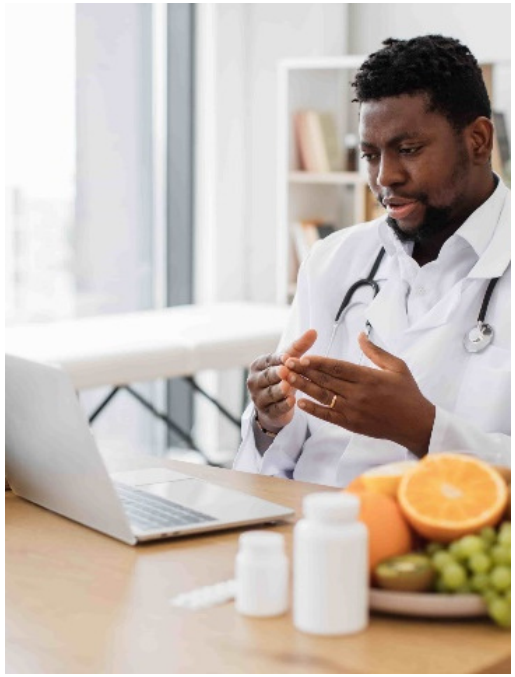
3. Matthews C. Co-developing a health literacy framework to integrate nutrition into standard care in SCD, Doctoral thesis, 2023..

The Health Delivery Framework (Matthews, 2023)



My Call To action – Sickle Cell Nutrition Academy (SCNA):

Nutrition



Education

Partnerships

SCNA: Activities and IMPACT 2023 to 2024

Recommendations: Our Call to Action

Nutritional Management

- 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

Policy and Practice change

- **Nutrition**
  - More Funding for nutrition service provision, and more specialist dietician roles in SCD – and tailored research
- **Education**
  - Support the development of tailored nutrition education and training modules and resources, embed in curriculum
- **Partnerships**
  - Engage with key stakeholders;
  - BDA, SCT APPG, NHSE, ICS, ICB, UKFHD, GP's, Service users/carers

Part Four:

4. Introducing the NHSE Nutrition Resources and Information

SICKLE CELL NUTRITION EATWELL GUIDE

Tailoring diet and nutrition knowledge and information to Sickle Cell Disease by increasing understanding of cultural and more sustainable foods enabling patients to better balance their diet and enhance health outcomes

CHOOSE HEALTHY OPTIONS

Use the traffic light system

Choose foods lower in fat, salt and sugars

Eat at least 5 portions of a variety of fruit and vegetables every day

Fruit and vegetables

TAMARIND

PAK CHOI

SOURSOP

OKRA

Regulate Immunity– include anti-oxidant foods

Reduce Inflammation

Choose a wholegrain or higher fibre versions with less added fat, salt and sugar

Potatoes, bread, rice, pasta and other starchy carbohydrates

BREAD

HARD DOUGH AND AGEGE

POTATOES / SWEET POTATOES

TARO ROOT

GREEN BANANA

YAMS

PORRIDGE

PLANTAIN

Include Energy Boosting Foods

PASTA

FUFU BANKU/ GARRI KENKEY

RICE

ROTI, INJERA

WHOLEGRAIN FLOUR

CORNMEAL

Eat more beans and pulses, 2 portions of sustainably sourced fish per week, one of which is oily. Eat less red and processed meat

Beans, pulses, fish, eggs, meat and other proteins

CHICKEN

CHICKPEAS

LENTILS

BEANS

Increase Protein Intake

MEAT (eat less of)

FISH

EGGS

Choose lower fat and lower sugar options

Dairy and alternatives

Almond

Yet

LOW FAT MILK

Improve Bone Health

Soy Drink

Eat less often and in small amounts

MALT BEVERAGE

PHOLOURIE

MEAT PIES

FRIED DOUGHS

CHOCOLATES AND SWEETS

PREVENT DEHYDRATION

8-10 per day

Water, lower fat milk, sugar-free drinks including tea and coffee all count.

Limit fruit juice and/ or smoothiesto a total of 150ml a day.

Oil

OILS AND SPREADS

Choose unsaturated oils and use in small amounts

Sickle Cell Nutrition Academy

SOURCE: 1. Public Health England in association with the Welsh Government, Food Standards Scotland, and the Foods Standards Agency, in Northern Ireland. 2. The Diverse Nutrition Association (African and Caribbean Eatwell Guide).

HOLISTIC SICKLE CELL NUTRITION EDUCATION MODEL







CLINICAL FEATURES	NUTRITIONAL SIGNS	LIFE STAGES		RED FLAGS	NUTRITIONAL INDICATORS	NUTRITIONAL ASSESSMENT
Chronic haemolysis anaemia and fatigue, high red cell turnover	Increased Energy and protein requirements Hyper-metabolism	• Paediatrics • Adolescents • Adults • Pregnancy • Elderly	**NUTRITION INTEGRATION IN SICKLE CELL DISEASE**	• Weight loss • Reduced appetite / intake • Ongoing poor appetite • Worsening complications • Frequent hospital admissions	• Underweight • Overweight • Increased infection risk	**MUST** Screening • Weight • Height • BMI • % weight loss • oral intake • food first advice
Vaso-Occlusion (crisis) tissue and organ damage	• Macro & Micro Nutrient Deficiency • Impaired Immunity • Increased oxidative stress • Delayed puberty				• Chronic anaemia and fatigue • Increased nutritional requirements	Refer to Dietitian, nutritional interventions, monitoring
• Impaired Immunity • Increased risk of infection						

NUTRITION POLICY AND PRACTICE | **HEALTH OUTCOMES** | **NUTRITION SERVICE PROVISION**

PEECE MODEL – Health Delivery Outcomes Tool

1.Prevention I 2.Education I 3.Empowerment I 4.Contextual Factors I 5.Engagement

SICKLE CELL NUTRITION > What you need to know! ①

Sickle Cell Disease (SCD) is a genetically inherited red blood cell disorder affecting nearly 17 500 people in the UK. SCD has both medical and nutritional features with the nutritional features directly linked to the main clinical features of the disorder. However, nutrition is only recently emerging as a management option in SCD care provision. This leaflet aims to provide an overview of the current nutrition landscape in SCD and the changes that are required to improve nutrition service provision.

SICKLE CELL NUTRITION

1. MARGINALISED
Nutrition not recognised as a problem to treat

2. INVISIBLE
Lack of nutrition knowledge and awareness

3. HEALTH INEQUALITY
Affects patients experience, access and outcomes

MAIN CLINICAL FEATURES

CHRONIC HAEMOLYSIS
Rapid breakdown 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

MAIN NUTRITIONAL FEATURES

1. High Resting Energy Expenditure
2. High Protein Turnover
3. High Red Blood Cell Turnover
4. Chronic Anaemia and Fatigue
5. Increased Cardiac Demand/ Expenditure
6. Increased Oxidative Stress
7. Chronic Inflammation
8. Impaired Immunity

INFLUENCING FACTORS:

SOCIO-ECOLOGICAL FACTORS AFFECTING NUTRITION:

Micro-level > Meso-level > Macro-level

NUTRITION ACROSS THE LIFE CYCLE:

Pregnancy · Paediatrics · Adolescents · Adults · Older Adults

WHAT IS REQUIRED?

1. To **INTEGRATE** nutrition into standard care provision in SCD.
2. To **IMPROVE** the knowledge and care gaps defining the nutrition landscape in SCD.
3. To **DEVELOP** nutrition policy and practice guidance in **SCD** and **FUND** more tailored research on nutritional management in SCD.

PEECE MODEL · PREVENTION · EDUCATION · EMPOWERMENT · CONTEXTUAL FACTORS · ENGAGEMENT

For more related resources :- www.sicklecellnutritionacademy.com

References:
Matthews C. Co-developing a health literacy framework to integrate nutrition into standard care in SCD, Doctoral thesis, 2022.

SICKLE CELL NUTRITION > Multi-level socio-ecological factors affecting nutrition and service provision ②

Sickle Cell Disease (SCD) is a genetically inherited red blood cell disorder affecting nearly 17 500 people in the UK. SCD has both medical and nutritional features, the nutritional features are directly linked to the main clinical features of the disorder.

CHRONIC HAEMOLYSIS → **VASO OCCLUSION** → **IMPAIRED IMMUNITY**

Rapid breakdown of red blood cells under low oxygen conditions

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

Impaired functioning of the spleen leading to increased risk of infection

However, nutrition is only recently emerging as a management option in SCD care provision requiring a greater need to tailor diet and nutrition knowledge and information to the specific needs of the sickle cell patients. This leaflet will highlight the multi-level socio-ecological factors affecting nutrition in Sickle Cell Disease.

MULTIPLE SOCIO-ECOLOGICAL FACTORS AFFECTING NUTRITION:

Micro-level (Personal and Interpersonal Factors) · Meso-level (Institutional Factors) · Macro-level (Community and Policy Factors)

Micro –level Factors	1.Personal Factors	Socio-economic, cultural, physical, time, religion, motivation, mood, pain, appetite, lack of nutrition knowledge
	2. Interpersonal	Stigma, lack of family support, peer pressure, nutrition not a priority for patients/clinicians, poor nutrition knowledge of the family
Meso-level Factors	3. Institutional Factors	Poor quality of hospital food, patients not referred to the dietitian, healthcare professionals with a poor knowledge of nutrition in SCD
Macro-level Factors	4.Community Factors	Access to cultural foods, distance to shops, lack of support for families, lack of good nutrition within the community and environments, social deprivation, poverty
	5. Policy Factors	Lack of trusted evidence based nutritional resources to support nutrition policy development, lack of nutrition service provision and poor recognition for nutrition education and training in SCD

SUMMARY:
To better understand and support the nutritional needs of sickle cell patients it is imperative to consider the socio-ecological factors, considering both internal and external factors influencing the patient's food security; their ability to buy, prepare and store, distance to stores, quality of food and additional support they may need to for effective decision making to make good nutritional choices.

For more related resources :- www.sicklecellnutritionacademy.com

References:
Matthews C. Co-developing a health literacy framework to integrate nutrition into standard care in SCD, Doctoral thesis, 2022.

SICKLE CELL NUTRITION > Managing the nutritional implications of Sickle Cell Disease ③

Sickle Cell Disease (SCD) is a genetically inherited red blood cell disorder affecting nearly 17 500 people in the UK. SCD has both medical and nutritional features with the nutritional features directly linked to the main clinical features of the disorder. However, nutrition is only recently emerging as a management option in SCD. This leaflet aims to provide an overview of how to manage some of the nutritional implications in SCD.

NUTRITIONAL IMPLICATIONS IN SICKLE CELL DISEASE:

CLINICAL FEATURES	HOW IT AFFECTS THE BODY	CONSEQUENCES	IMPACT
CHRONIC HAEMOLYSIS	The rapid breakdown of red blood cells under low oxygen conditions in the blood	Chronic anaemia and fatigue, increased red blood cell turnover, low oxygen levels in the blood, increased oxidative stress leading to chronic inflammation	High Resting Energy Expenditure (REE) High protein turnover High red blood cell turnover
VASO OCCLUSION	The blockage of small and large blood vessels with sickle shaped red blood cells	Reduced or obstruction of blood flow in blood vessels, leading to tissue or organ damage and chronic inflammation	Increased cardiac demand/expenditure Chronic anaemia and fatigue
IMPAIRED IMMUNITY	Impaired functioning of the spleen	An increased risk of infection, increased nutritional requirements and chronic inflammation	Increased oxidative stress Chronic inflammation Impaired immunity

KNOW THE SIGNS AND SYMPTOMS IMPACTING YOUR NUTRITIONAL RISKS

Share your nutritional concerns with your healthcare professional or GP if you:

- Have a poor appetite
- Have lost weight unintentionally
- Not able to regain your weight after illness
- Worsening anaemia or fatigue
- Multiple or long lasting infections
- Frequent hospital admissions
- Worsening complications
- Not able to engage in activities of daily living

MAINTAINING GOOD NUTRITIONAL PRACTICES FOR GOOD HEALTH

Consider the following to prioritise good nutrition and help you maintain good health:

- Aim to eat at regular intervals
- Use the Sickle Cell Nutrition: Eat Well Guide to help choose healthy options
- Eat little and often when your appetite is small
- Have energy dense snacks (high in protein and carbohydrates) in between your meals - see SCD Eatwell Guide
- Enrich/Fortify your meals and snacks to increase your protein and calorie intake
- You may need a nutritional supplement if there is no change in your appetite or you are losing weight

For more related resources :- www.sicklecellnutritionacademy.com

References:
Matthews C. Co-developing a health literacy framework to integrate nutrition into standard care in SCD, Doctoral thesis, 2022. 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. 37-67

SICKLE CELL NUTRITION > Optimising nutrition in Sickle Cell Disease ④

Sickle Cell Nutrition is an emerging management option in Sickle Cell Disease. Therefore, addressing the nutritional deficiencies, growth delays and nutritional risks linked to the clinical features of the condition, is essential. This leaflet provides an overview of how to optimise the nutritional status of people affected by SCD. Below are 3 key factors to consider:

1. RECOGNISE HOW SICKLE CELL AFFECTS YOUR NUTRITIONAL NEEDS:

CHRONIC HAEMOLYSIS · VASO OCCLUSION · IMPAIRED IMMUNITY

IMPACT	NUTRIENTS
• High Resting Energy Expenditure • High protein turnover • High red blood cell turnover • Increased cardiac demand/expenditure • Chronic anaemia and fatigue • Increased oxidative stress • Chronic inflammation • Impaired immunity	**Macro nutrients:** • Carbohydrates • Fats • Proteins **Micro-nutrients:** • Vitamins (A, C, E, D, Folic acid) • Minerals (Zinc, Selenium, Iron) • Omega 3 Fatty acids

Micro-level (Personal and Interpersonal Factors) > Meso-level (Institutional Factors) > Macro-level (Community and Policy Factors)

2. MAKE GOOD NUTRITIONAL CHOICES ! TIPS AND CHOICES TO HELP OPTIMISE NUTRITION

ENERGY BOOSTING	INCREASED PROTEIN	HEALTHY IMMUNITY	BONE HEALTH	GUT HEALTH
Include carbohydrate rich food and healthy fats to manage your increased energy requirements	Include protein rich food to build and repair cells, tissues and build new red blood cells	Include antioxidant and anti-inflammatory rich foods as well as vitamins and immune regulating micro nutrients	Include dairy products and optimise your Vitamin D intake to support bone density and health	Include a variety of fruit, vegetables and wholegrains to promote a healthy gut. Be aware of the risk of opioid related constipation and drug/ food interactions

3. CONSIDER ADDITIONAL NUTRITIONAL FACTORS TO OPTIMISE YOUR HEALTH OUTCOMES

REDUCED APPETITE	LOSING WEIGHT UNINTENTIONALLY	INCREASE IN WEIGHT
Consider, • Eat little and often • Eat foods you enjoy • Keep healthy snacks to hand • Have nourishing drinks (eg.milk-based drinks) • Have energy dense foods and snacks	**Consider,** • Eating regular meals and snacks • Don't skip meals • Choose high nutrient density foods and snacks • Have a bed time snack • Be flexible with your food choices	**Consider,** • Energy intake and output • Monitor portion sizes • Reduce intake of high fat and sugar snacks • Reduce take away meals, eat from home • Make small manageable changes

For more related resources :- www.sicklecellnutritionacademy.com

References:
Matthews C. Co-developing a health literacy framework to integrate nutrition into standard care in SCD, Doctoral thesis, 2022. 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. 37-67

SICKLE CELL NUTRITION > How to Eat Well to Live Well with Sickle Cell Disease ⑤

Considering nutrition as a management option in Sickle Cell Disease (SCD) plays an important role in enabling people affected by sickle cell to Eat Well and Live Well. This leaflet aims to empower people affected by sickle cell to Eat Well to prepare them to better self-manage their condition.

HELPFUL SUGGESTIONS TO EAT WELL WITH SICKLE CELL.

1.PLANNING TO EAT WELL
- Follow healthy eating guidelines – see SCD Eatwell guide
- Prioritise your health
- Identify your health goals
- Choose healthy options to match your goals
- Take advantage of help available

2.EATING WELL ON A BUDGET
- Make a meal plan and a shopping list
- Take stock of what you already have available
- Use tinned, frozen and dried food options
- Buy value brands as much as possible
- Reduce takeout meals and lunch options

3.EATING WELL WHEN FATIGUED
- Ask for help from family and friends
- Have healthy snacks to hand – nuts, dried or fresh fruit cut up.
- Have nutritious drinks available – milk based, fruit smoothies
- Prepare meals in advance, freeze meals
- Choose healthy meal and snack options over high fat and sugar options

4.EATING WELL WITH A LOW APPETITE
- Eat little and often
- Choose high protein foods and snacks
- Fortify your meals and snacks – grated cheese, pea or soy protein powder
- Have nourishing drinks – milk based or alternatives
- Have energy dense snack in between meals – nuts, dried fruit, egg, crackers

5.EATING WELL WHEN UNWELL
- Don't skip meals
- Choose foods you enjoy eating - as tolerated
- Focus on choosing high protein and energy dense meals and snacks
- Avoid low energy food and drink options- skimmed and semi-skimmed milk options
- Use nutrient dense food fortifiers (cheese, butter, cream)

6.EATING WELL WHEN IN CRISIS AND DURING RECOVERY
- Prioritise nutrition as much as possible
- Prioritise high energy and protein foods, snacks and drinks
- Have nourishing drinks if eating is a problem
- Eat smaller meals and snacks throughout the day
- Choose foods you enjoy eating

SUMMARY:
Tailoring the nutritional advice to the unique health and social care needs of people affected by SCD is an essential part of enabling and empowering those individuals to Eat Well to Live Well!

For more related resources :- www.sicklecellnutritionacademy.com

References:
Matthews C. Co-developing a health literacy framework to integrate nutrition into standard care in SCD, Doctoral thesis, 2022. 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. 37-67

SICKLE CELL NUTRITION > Nutritional strategies for common nutritional problems in Sickle Cell Disease ⑥

Considering nutrition as a management option in Sickle Cell Disease (SCD) plays an important role in enabling people affected by sickle cell to Eat Well and Live Well, therefore diet and nutrition knowledge needs to be tailored to SCD. This leaflet aims to provide nutritional strategies to manage the common nutritional problems specific to the needs of sickle cell patients to improve their health and wellbeing outcomes.

NUTRITIONAL STRATEGIES FOR COMMON NUTRITIONAL PROBLEMS IN SICKLE CELL DISEASE:

COMMON NUTRITIONAL PROBLEMS: MALNUTRITION · ANAEMIA /FATIGUE · POOR IMMUNITY/ CHRONIC INFLAMMATION · IRON OVERLOAD · CONSTIPATION/DEHYDRATION · OSTEOPOROSIS /PICA

MALNUTRITION

Reduced intake of:
- Protein
- Energy
- Micronutrients
- Reduced appetite
- Reduced food intake
- Weight loss

Food first advice
- Fortify food and drinks
- Fortify to increase protein and energy
- Choose Energy dense foods
- Eat little and often

Oral nutritional supplements
- Prescribed (requires a nutritional assessment)
- Over the counter Supplement sachets –made up with milk
- Ready made supplements
- Variety

CHRONIC ANAEMIA AND FATIGUE

Chronic Anaemia (low energy and tiredness)
- Eating little and often
- Increase intake of energy dense foods
- Food fortification
- Good sources of iron rich foods (if not iron overloaded)
- Folic acid (green leafy veg, broccoli, avocado, citrus fruits, whole wheat)
- Regular gentle activity/exercise

Fatigue
Factors affecting fatigue
- Physical
- Emotional
- Mental
- Environmental
- Socio-economical

POOR IMMUNITY/ CHRONIC INFLAMMATION

Poor Immunity
- Increased risk of infection
- Increased risk of malnutrition
- Increase need for Protein and energy foods
- Food hygiene – wash foods, check expiry dates
- Vitamin D (sunshine, fatty fish, eggs, butter, supplements)
- Selenium – (brazil nuts, fatty fish)
- Zinc – (pecan nuts, eggs, fish, poultry, beans)

Chronic Inflammation
- Oxidative stress
- Tissue and cell damage

Anti-oxidant foods:
- Vitamin A, C, E – 5 a Day

Anti-inflammatory foods:
- Omega 3 – (salmon, mackerel, sardines, tuna, walnuts, walnut oil, flaxseeds/oil, chia seeds, canola oil)
- Supplements – check with your HCP

SUMMARY:
Managing the nutritional needs of people affected by SCD, tailored to their unique nutritional needs, risks and challenges is fundamental to promoting their wellbeing and health outcomes, thereby enabling them to Live well with Sickle Cell.

For more related resources :- www.sicklecellnutritionacademy.com

References:
Matthews C. Co-developing a health literacy framework to integrate nutrition into standard care in SCD, Doctoral thesis, 2022. 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. 37-67

SICKLE CELL NUTRITION > Nutritional strategies for common nutritional problems in Sickle Cell Disease ⑥ (Continued)

Considering nutrition as a management option in Sickle Cell Disease plays an important role in enabling people affected by sickle cell to Eat Well and Live Well. Tailoring diet and nutrition knowledge and information to the specific needs of people affected by sickle cell disease is therefore essential.

NUTRITIONAL STRATEGIES FOR COMMON NUTRITIONAL PROBLEMS IN SICKLE CELL DISEASE:

COMMON NUTRITIONAL PROBLEMS: MALNUTRITION · ANAEMIA /FATIGUE · POOR IMMUNITY/ CHRONIC INFLAMMATION · IRON OVERLOAD · CONSTIPATION/DEHYDRATION · OSTEOPOROSIS /PICA

DEHYDRATION/ CONSTIPATION

Pain medication
- Affect nerve endings in the bowel
- Cause bowels to be sluggish
- Slow movement of stool through the bowel
- Frequent Hospitalisation – can increase malnutrition risk

Constipation
Fibre:
- Wholegrains, brown rice, brown pasta, nuts, seeds
- Fruit and Veg – 5 a Day

Fluid:
- 8-10 cups of fluid
- Water, herbal tea, fruit squash

Fun Activity:
- 150 minutes of activity 5 days a week
- Cleaning, walking, yoga, pilates, swimming

IRON OVERLOADING

If you have iron overloading you will,
- have to limit the amount of iron taken in through your diet
- be compliant with your iron chelation regime.

What you can have in your diet,
- You can have fruits and vegetables, grains and legumes, eggs, lean protein sources, like chicken or turkey,

Consider:
- tea and coffee can also reduce iron absorption
- reduce your intake of vitamin A and C rich foods (these foods enhance iron absorption),
- Reduce foods fortified with iron
- Avoid supplements containing iron

OSTEOPOROSIS/PICA

OSTEOPOROSIS
Risk factors:
- Low weight, Low Vitamin D level, haemolysis, inflammation, hypogonadism

Diet:
- Vitamin D – Regulates Calcium absorption
- Calcium – dairy products (Calcium fortified dairy alternatives), brazils, tofu, green leafy veg, sardines with bones, wholegrains
- Phosphorous – dairy, red meat, poultry, seafood, legumes and nuts
- Physical activity

PICA
- Low Heamoglobin levels
- Eating non-food items
- Look out for it
- Speak to your GP or health visitor
- Check overall diet

SUMMARY:
Managing the nutritional needs of people affected by sickle cell disease, tailored to their unique nutritional needs, risks and challenges is fundamental to promoting their wellbeing and health outcomes, thereby enabling them to Live well with Sickle Cell.

For more related resources :- www.sicklecellnutritionacademy.com

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SICKLE CELL NUTRITION > Considering key nutritional factors across the life cycle in Sickle Cell Disease ⑦

Considering nutrition as a management option in Sickle Cell Disease (SCD) plays an important role in enabling people affected by sickle cell to better self –manage their condition. The aim of this leaflet it to raise awareness of some of the key nutritional factors affecting sickle cell patients across the life cycle and empower both the patients and healthcare professionals to enable patients to improve their health and wellbeing outcomes.

NUTRITION ACROSS THE LIFE CYCLE:

Pregnancy · Paediatrics · Adolescents · Adults · Older Adults

KEY NUTRITIONAL FACTORS TO BE AWARE OF ACROSS THE LIFE CYCLE:

PAEDIATRICS		ADOLESCENTS	
STAGES	WHAT TO LOOK OUT FOR	STAGES	WHAT TO LOOK OUT FOR
• Weaning (6 months) • Toddlers (2years) • School age (4 years)	1. Common nutritional problems; • Growth failure, Failure to thrive, Fussy eating • Reduced appetite/intake • Pica 2. Support for parents and caregivers 3. Regular assessment and monitoring of nutritional health 4. Referral to dietitian for specialist nutritional support 5. Access to tailored nutrition education and resources	• Transitioning age (from 11years) • Young Adults	1. Common nutritional problems; • Delayed puberty • Delayed menarche 2. Assess and monitor malnutrition risk (Baseline MUST Score) 3. Monitor infection risk – compliance with medication) 4. Monitor appetite, quality of diet and food choices 5. Provide access to tailored nutrition education, resources and support

WHAT TO LOOK OUT FOR

ADULTS	PREGNANCY	OLDER ADULTS
1. Assess and monitor malnutrition risk (baseline MUST score) 2. Consider impact of chronic anaemia and fatigue on activities of daily living 3. Monitor worsening complications and its impact on nutrition 4. Assess frailty risk secondary to complications 5. Monitor frequency of crisis and resulting hospital admissions 6. Assess and manage the side effects of the treatment modalities on nutrition (constipation, nausea) 7. Provide access to tailored nutrition education, resources and support	1. Assess and monitor malnutrition risk – (ante and postnatal checks) 2. Assess nutritional risks 3. Monitor regular meals, snacks and supplements (Folic acid, Vitamin D) and (iodine, omega 3- fatty acids, Vitamin B12) in plant based diets 4. Avoidance of alcohol and smoking 5. Ensure good food hygiene 6. Preventing dehydration 7. Monitor appetite and nutritional intake 8. Monitor pregnancy side effects (constipation, heartburn, nausea)	1. Assess overall malnutrition risk and baseline MUST score; • Check appetite and intake • Monitor access to food • Check support with shopping and meal preparation 2. Assess frailty risk and impact on nutritional status 3. Assess any additional age related needs, risks impacting nutrition 4. Monitor worsening complications and hospital admissions 5. Monitor any changes in appetite 6. Improve access to tailored nutrition advice and support

For more related resources :- www.sicklecellnutritionacademy.com

References:
Matthews C. Co-developing a health literacy framework to integrate nutrition into standard care in SCD, Doctoral thesis, 2022.

SICKLE CELL NUTRITION > Glossary of common nutritional terms in Sickle Cell Disease ⑧

Considering nutrition as a management option in Sickle Cell Disease (SCD) plays an important role in enabling people affected by sickle cell to better self –manage their condition. Thus, the aim of this glossary is to raise awareness of the key nutritional features directly caused by the main clinical features of SCD, pivotal to improving the knowledge of both patients and healthcare professionals managing the nutritional needs of sickle cell patients, to improve their health outcomes.

MAIN CLINICAL FEATURES: NUTRITIONAL CONSEQUENCES

CLINICAL FEATURES	NUTRITIONAL CONSEQUENCES
CHRONIC HAEMOLYSIS	Chronic anaemia and fatigue, increased red cell turnover, increased cardiac demand/ expenditure, increased oxidative stress, chronic inflammation
VASO OCCLUSION	Ischaemia and obstruction of blood flow in large and small blood vessels causing cell and tissue damage and chronic inflammation
IMPAIRED IMMUNITY	Increased risk of infection and increased risk of malnutrition

GLOSSARY OF NUTRITIONAL TERMS:

COMMON NUTRITIONAL TERM	EXPLANATIONS
Sickle Cell Nutrition	The nutritional implications of SCD caused directly by the main clinical features of the condition
Holistic Sickle Cell Nutrition	The cumulative cassatum of the nutritional, medical, socio-economic and socio-ecological factors affecting the nutritional needs of patients impacting their health and wellbeing outcomes
High Resting Energy Expenditure	High rate of energy used by the body while at rest
High protein turnover	High rate of protein replaced by cells
High red cell turnover	High rate by which red blood cells are made and replaced
Chronic anaemia and fatigue	When the body does not get enough oxygen rich blood, this can cause fatigue due to a lack of oxygen
Increased cardiac demand	The amount of oxygen the heart needs to function properly
Cardiac expenditure	The amount of oxygen the heart uses
Increased oxidative stress	The imbalance of harmful substances that can cause cell and tissue damage
Impaired Immunity	When the immune system does no work properly to protect against infections
Chronic Inflammation	Long term inflammation lasting for extended periods of several months or years
Pica	The eating or craving of things that are not food
Osteoporosis	A health condition that weakens bones, making them fragile and more likely to break

For more related resources :- www.sicklecellnutritionacademy.com

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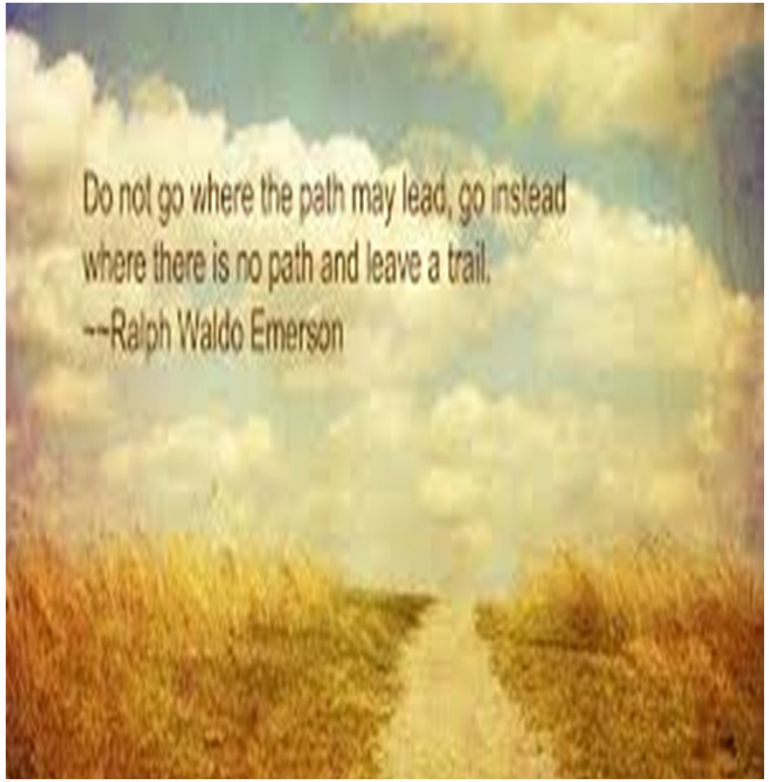

Thank You!

"Every closed door brings you closer to your Destiny"
Dr Claudine Matthews

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