

Department of nutrition and dietetics

Nutrition and sickle cell disease

Information for patients, relatives and carers

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Introduction

People with sickle cell disease can be at risk of poor nutrition. This is because sickle cell disease puts demands on the body that use up a lot of energy and protein. During a sickle cell crisis nutritional intake can be further affected by reduced appetite. This can be caused by pain, painkillers and low mood.

This booklet explains how nutrition can help people with sickle cell disease to maintain good health and prevent infections.

The booklet is divided into three parts:

Part one: outlines the five food groups. This section also explains healthy eating.

Part two: discusses eating if you have a poor appetite or are needing to gain weight.

Part three: gives ideas for snacks and recipes to get you started on a healthier eating pattern.

Part One: Healthy eating and the food groups

Why is a healthy diet important?

As well as being enjoyable, food and drinks are vital in providing all the essential nutrients our body needs to function. There is no diet to cure sickle cell disease. But sensible eating may help you to avoid some of the effects of sickle cell.

Also, some medications for sickle cell disease need to be taken with or just after a meal, so it is important to have good nutrition to support this.

A good diet should give us energy (calories), protein, fibre, vitamins and minerals. Because no single food or a group of foods contains all these nutrients, it is important that we eat a variety of foods. Ideally, foods from each of the **5 food groups** should be eaten daily.

Try to eat regular meals and snacks each day and include the recommended servings of each food group into the diet to support getting the nutrients your body needs.

Fluids

Drinking enough fluids is very important in sickle cell. Not drinking enough water (becoming dehydrated) is one of the most common causes of sickle cell crisis. The blood can become thicker and, as a result, sickled shaped red blood cells are more likely to stick together and cause a blockage.

If you have trouble sleeping, it's best to avoid drinking tea and coffee after midday. Caffeine has a long half-life and may make it difficult for you to sleep. Drink alcohol in moderation and within the recommendation of less than 14 units a week.

The 5 food groups

- 1 **Starchy food (carbohydrates or 'carbs')**
- 2 **Protein**
- 3 **Dairy and alternatives**
- 4 **Fruit and Vegetables**
- 5 **Fats, Oils and Spreads**

Remember to drink lots of fluids, especially water (up to 8 to 10 cups or 2 to 3 litres a day)

1. Starchy foods (carbohydrates)

Starchy food (carbohydrates) are foods that give us **energy** (calories) in the diet. They should form the main part of most meals and snacks.

Examples of starchy foods include bread, breakfast cereals, potatoes, plantain, yam, green banana, chapatti, naan, rice and pasta.

Wholegrain varieties of starchy foods for example, wholemeal bread, rice and pasta are also a good source of fibre and B vitamins.

Fibre helps to keep your bowels healthy. It can relieve and prevent **constipation**. When increasing the amount of fibre in your diet you should also make sure you drink plenty of **fluid**.

How much starchy food do I need to eat?

This varies from person to person, depending on their needs, but 1/3 of your plate should be starchy food. Eat some starchy food at every mealtime.

2. Protein foods

Protein foods provide the building materials for growth and repair of body tissue such as muscles, skin, blood and bones. They are also sources of energy (calories).

Protein sources include:

- beans, pulses (for example, lentils or chickpeas), nuts and seeds
- beef, pork, lamb, chicken, turkey, fish and eggs
- tofu, soya mince or meat, Quorn™, soya beans

Try to:

- choose lean meat or remove excess fat or skin
- eat less processed meat (such as sausages, for example)
- include two portions of fish each week. One of these should be an oily fish, like mackerel, trout, sardines, kippers
- include plant-based sources of protein in your diet regularly

Meals built on starchy foods

Breakfast:

- wholemeal toast, breakfast cereal,
- yam or ogi

Lunch:

- jacket potato, sandwich with wholemeal bread
- jollof or fried rice with moi moi
- cous cous or yam, garri (eba) or kenkey

Supper:

Base this on:

- rice, pasta, potatoes
- fufu, pounded yam, green plantain or cassava

Then add protein:

- chicken, lean meat, fish, cheese, egg or pulses

How much protein do I need?

This varies from person to person, but it's about **2 to 3 servings daily**

One serving equals:

- 2 eggs
- 1 breast of chicken
- 1 piece of fish the size of your hand
- 1 slice of ham, beef or lamb or a pork or lamb chop
- 125g to 150g cooked beans or pulses. For example, a small tin of baked beans

3. Dairy and alternatives

Dairy foods are an excellent source of **calcium**. If you plan to eat less dairy, many plant-based foods contain good amounts calcium too.

Calcium is necessary for growth and repair of bones and teeth. When you rest in bed for long periods, bones lose calcium. Over many years this can weaken the bones (For some people this may increase your chances of bone fractures.) So, it's important to ensure you have a good source of calcium in your diet.

Excellent calcium sources include:

- milk, cheese and yogurt
- calcium-fortified plant-based drinks, yogurts or tofu
- white bread, tinned fish (for example, sardines, salmon), leafy green vegetables (for example, spinach, cabbage, broccoli), nuts and seeds, oranges, orange juice with added calcium, dried fruit (for example, apricot, figs)

How much calcium do I need?

A rough guide is **3 servings daily**

One serving equals:

- 1/3-pint milk
- 150g (1 pot) yoghurt
- 25g (1 oz) cheese

Any combination of these foods listed is suitable if you have 3 servings a day. For example, 1/3-pint milk + 50g (2 oz cheese) = **3 servings**

Remember: some of these foods also have a high fat content. To reduce fat content, choose reduced fat products, like semi-skimmed milk, low fat yogurt, reduced fat cheese.

4. Fruit and vegetables

Fruit and vegetables are a great source of vitamins and minerals in the diet. They're also a very good source of fibre. Any fruit and vegetables are suitable. Fresh, tinned (in natural juice) and frozen are all healthy options.

Everyone produces toxic substances called 'free radicals' which can cause damage to tissues. People with sickle cell may produce more of these, especially during a sickle cell crisis. Certain vitamins and minerals (antioxidants) especially vitamin **A**, **C**, **E** and **selenium** can help to protect the body from such damage when obtained from food.

Foods rich in antioxidants	
Vitamin A	carrots, tomatoes, red peppers, cabbage, spinach, broccoli, sweet potato, aubergines, mango, plums, melon, apricots, fufu, curly kale, passion fruit, guava, paw paw, spring greens
Vitamin C	most fruit and vegetables, but particularly: citrus fruits like lemons, grapefruit, oranges, strawberries, red and green pepper, leafy green vegetables (for example, broccoli, cabbage; cauliflower, Brussels' sprouts, watercress, spring greens)
Vitamin E	wholemeal bread, wheat germ, egg yolk, vegetable oils, margarine, nuts (for example, almonds, hazelnuts, peanuts), sesame and sunflower seeds, avocado
Selenium	wholemeal bread, beans (for example, mung beans, kidney beans, black-eyed beans), lentils, nuts, fish, chicken, lean beef

Aim to get at least 5 servings of fruit and vegetables every day. One serving of fruit equals:

- 1 apple, orange, banana
- 2 plums, satsumas
- 2 handful of berries
- 1 glass orange juice (only 1 glass a day counts towards your 5 a day)

One serving of vegetables equals:

- 3 heaped tbsp of vegetables
- 1 cereal bowl of lettuce, spinach

5 servings a day may sound a lot at first. But below is an example of how you can introduce fruits and vegetables into your daily eating pattern.

- fruit added to breakfast
- 2 servings of vegetables with your main meal
- fruit for a pudding
- fruit for a snack

General points

Certain cooking methods and ways of storing food can lower their vitamin and mineral content. So, try to:

- cook in minimal amounts of water. Try steaming vegetables
- if available, microwaving vegetables is a good way of preserving vitamins
- try fresh fruit or raw vegetables for snacks in-between meals
- store fruit and vegetables in dark places, out of direct sunlight
- frozen vegetables are a convenient way to increase your vitamin and mineral intake

Other important vitamins and minerals

Iron

Only take iron supplements after talking to the specialist red cell team, and when you've got laboratory confirmation of iron deficiency.

Folate or folic acid

People with sickle cell disease need extra folate to support the production and development of new red blood cells.

Folic acid can be found in food such as fortified cereal (for example, Special K™, Bran Flakes™, muesli, Oat & Bran Flakes™ with added vitamins and minerals), wholemeal and grainy bread, asparagus, Brussel sprouts, spinach, chickpeas, soya, lamb and peanuts.

How much folate do I need?

In the UK, the recommended daily intake of folate for the standard adult population is 200 micrograms of folate (ideally through their diet). **But if you have sickle cell disease, you'll be recommended to have a higher dose by taking a supplement each day. This is a 5 micrograms dose of folic acid taken by mouth (orally).**

This is because some studies have shown that people with sickle cell have lower levels of folic acid compared to healthy individuals (Standards for Clinical Care of Adults with Sickle Cell Disease, 2018).

See the folate content of some common foods in the table below:

Folate content of common foods

Food	Folate (micrograms = µg)
Medium portion (30g) of Bran Flakes™, Rice Krispies™ or cornflakes	100 µg
Special K™ (50g)	167 µg
Granary bread (2 slices)	69 µg
Wholemeal bread (2 slices)	30 µg
Spinach (average serving, 90g)	73 µg
Brussel sprouts (medium portion)	99 µg
Black-eyed beans (small portion, cooked)	105 µg
Peanuts (40g)	55 µg

Zinc

Red blood cells are broken down more quickly in people with sickle cell. Zinc prolongs the life span of red blood cells. People with sickle cell are also shown to be deficient in zinc.

Good sources of zinc include oysters, lean meat, beans, nuts, seeds, breakfast cereals with added vitamins and minerals, fruit and vegetables.

Vitamins and minerals supplements

If you've got a balanced and varied diet, this should provide you with enough vitamins and minerals, except for vitamin D.

We generally do not recommend taking multi-vitamin supplements (except vitamin D). Excessive amounts of some vitamins, including those marketed as 'antioxidant', can be harmful. But if you feel you need multi-vitamin supplement, talk to your dietitian or doctor.

Vitamin D

Works with calcium and phosphorus for healthy bones, muscles and teeth.

- most of the vitamin D we need is made under our skin when we are outside. This is especially so during spring and summer months where it is sunnier

-
- vitamin D is also found in a small number of foods. These include oily fish, red meat, liver, egg yolks, fortified foods such as most fat spreads and some breakfast cereals

The Department of Health and Social Care recommend that:

- the standard adult population should consider taking a daily oral supplement containing **10 micrograms (equivalent to 400 units) of vitamin D during autumn and winter.**
- all adults in at risk of low vitamin D levels groups should consider taking **10 micrograms (equivalent to 400 units) of vitamin D all year round**

People with sickle cell, are more likely to have vitamin D deficiency. So, it's ideal to have your vitamin D level checked 6 to 12 monthly.

If very low (deficient) vitamin D levels are detected in your blood, your doctor may prescribe a short course of a higher treatment dose vitamin D for you to take. This will be followed by a standard daily maintenance dose.

Please speak to your doctor if you have any questions or concerns about this.

At risk groups include:

- people with darker skin tones (people of Asian, African, Afro-Caribbean and middle eastern descent) living in the UK or other northern climates
- pregnant women and breastfeeding mothers
- people over 65 years old, because their skin is not as good at making vitamin D
- people who always cover most of their skin when are outside
- anyone who spends very little time outside during the summer – the housebound or frail, shop or office workers, night shift workers

5. Fats, Oils and Spread

Fats provide us with energy (calories) as well as some essential vitamins.

This group includes butter, margarine and spreads, cooking oils (for example, olive, rapeseed, vegetable, sunflower, and palm oils).

There are two types of fats:

- unsaturated (healthy)
- saturated (unhealthy)

Oils and spreads contain some essential vitamins (vitamins A, D, E, K) which are important to the body. But too much of some of these oils and spreads can be unhealthy, especially if they

are high in saturated fat. Try to choose spreads and oils that are low in saturated fat, like olive oil, sunflower oil, rapeseed oil or vegetable oils or spreads made from these oils.

Animal fats (like butter or lard) and **some oils** (like palm or coconut oil) are high in saturated fat. Having too much saturated fat in the diet can lead to heart disease.

Most of us would benefit from **eating less fat**, especially if we're overweight, as this will result in a lower calorie intake. So:

- use fats and oils sparingly on bread and in cooking
- use more of the vegetable fat and oils (like olive oil or sunflower oil) than animal fats
- beware of invisible fats in foods like biscuits, cakes, chocolate, crisps, and pastries. These foods have little nutritional benefit, other than excess calories.

How many meals do I need each day?

Aim to eat **3 regular meals** a day. These should contain a mix of the 5 food groups explained above. This will make sure you're getting a range of nutrients in your diet.

There may be times when you've got a poor appetite because of a painful sickle cell crisis or due to painkillers. You might not have much energy to prepare your meals.

If this happens, you may not feel like eating big meals. Eating 'little and often' at these times could be a better option for you (see the next section for further advice).

Taking care with 'junk' food

It can be easy to reach for 'junk' type foods, like chocolate, sweets, crisps and sugary drinks.

Though these can help when your appetite and energy intake is low, they should not be part of your regular diet. You can enjoy them, but only sometimes.

These foods fill you up for an hour or so. But they often do not contain many important vitamins and minerals.

If you have a junk food diet for long time you will be at an increased risk of developing diet related conditions such as type 2 diabetes or high cholesterol levels.

Remember, a 'healthy diet' is:

- 1 **varied and balanced**
- 2 **low in saturated fat**
- 3 **low in sugar**
- 4 **high in fibre**

So, try to get back to a healthier diet with a regular meal pattern as soon as you feel better.

Part Two: Increasing your energy and protein intake

There may be times where you may need to increase your energy and protein intake. This could be when you have a decreased appetite, you have lost weight without trying or you are underweight. Energy (calories) is important to maintain weight and manage daily activities. Protein plays an important role in maintaining your muscles.

What to do if you do not feel like eating?

Sometimes your appetite is poor, and you do not feel like eating. This can happen during a crisis, for instance. When this happens, it's very important to try to continue eating regularly. This will help to prevent weight loss. Try not to lose weight without meaning to, as this can delay your recovery.

Ways to get nutrition if you've got no appetite

Drink more nourishing drinks.	Have milk or milkshakes, yogurt drinks, fruit smoothies with milk. Or use full cream milk to make hot drinks like drinking chocolate, Ovaltine™ and Horlicks™
Avoid drinking large amounts of liquids at mealtimes.	Drinks with meals can make you feel full and limit how much food you are able to eat. Instead drink plenty in-between mealtimes.
Try high protein drinks available from your chemist.	Useful if you cannot face eating. Examples include Meritene Strength & Vitality™, Complan™, Nurishment™.
Switch to small meals or snacks throughout the day	'Little and often' is the key. See snack suggestions below.

Snack suggestions: food to have handy for between meals

nuts, chin chin, crisps	dips, like houmous, guacamole, taramasalata, with crackers or vegetable stick	cheese and biscuits
sandwiches – cheese, tuna, egg, add extra mayonnaise	yoghurt, dried or fresh fruit	toast with scrambled egg, jam, marmalade or honey
biscuits, cake, puff puff, croissants, pastries	garri with water, moi moi	oatcakes, crumpets teacakes with cream cheese, nut butter or jam

Ways to add more energy (calories) and protein into your diet

If you have a poor appetite or have experienced unintentional weight loss, you'll benefit from adding extra energy (calories) and protein to your diet. Here are some ideas.

Start with	Boost energy with
breakfast cereals	<ul style="list-style-type: none">• dried fruit, nuts, seeds• honey to porridge or yoghurt• use fortified milk (see recipe)
vegetables and salads	<ul style="list-style-type: none">• grated cheese, crumbled feta• salad dressing, mayonnaise• chopped egg, beans, nuts and seeds on salad• margarine, butter, oils on hot vegetables• sauces (for example, cheese sauce) on vegetables
saucers	<ul style="list-style-type: none">• Greek, full cream, soya or coconut yogurt• evaporated milk, cream, coconut, soya or oat cream• grated cheese, cream cheese• margarine, butter
soups and casseroles	<ul style="list-style-type: none">• grated cheese• beans, lentils, noodles, pasta, pearl barley• double or soya cream, crème fraiche, butter, margarine• fortified milk, coconut milk, milk powder
mashed potato	<ul style="list-style-type: none">• grated cheese• double cream• butter, margarine, oil• chopped hardboiled egg• salad cream, mayonnaise
puddings	<ul style="list-style-type: none">• fortified milk when making milk puddings or instant desserts (for example, rice pudding, custard, blancmange)• evaporated milk to cold puddings, extra sugar, jam or honey to sponge or milk puddings• dried fruit, chopped nuts

	<ul style="list-style-type: none"> • Greek, full cream, soya or coconut yogurt • ice cream • cream, clotted cream, custard on a cake
drinks	<ul style="list-style-type: none"> • use fortified milk or whole milk instead of water when making coffee and bedtime drinks, like Horlicks™, hot chocolate and Ovaltine™ • drink glasses of whole milk or milkshakes with ice cream added • liquidise ice cream with tinned fruit for a 'quick shake' • try yoghurt drinks or fruit smoothies

Note: food rich in fat (like margarine, butter, oil or cream) and food rich in sugar (like sweets, jam, honey, chocolate and sugar) are a useful source of energy. But these often have very little nutritional benefit other than excess calories (energy).

How to make fortified milk: add 2 tbsp milk powder to 1 pint of whole milk and mix well. Use as normal in drinks and cooking

Part Three – Food ideas

Wake up to a healthy breakfast

Breakfast is an essential start to the day. So, try not to miss it. Here are some ideas!

Toast – choose wholemeal bread, as it's higher in fibre and B vitamins

Try the following ideas on your toast:

- jam, marmalade, or peanut butter, Marmite™ or other yeast extracts
- mashed banana, mashed avocado
- baked beans (also a source of protein)
- poached or scrambled egg (also a source of protein)

Yoghurt – an easy food to eat at breakfast, this is an excellent source of calcium and protein. Try low fat plain or fruit flavoured varieties and mix with muesli or fruit.

Breakfast cereals – high-fibre varieties are the best choice for cereal. So, think Weetabix, Shredded Wheat™, All Bran™, Bran flakes™ or muesli.

To give variety try adding the following

- slices of fresh fruit, like apple, pear, banana, blueberries
- dried fruits, like raisins, currants, apricots, prunes

- yoghurt

Porridge – made with semi-skimmed milk

Try adding dried fruit or yoghurt. If you like porridge but find it difficult to make, try the instant varieties such as Ready Brek™ and Oats so Simple™.

Lean grilled bacon – served with tinned tomatoes, mushrooms or baked beans, served with wholemeal toast.

Yam – boiled and served with scrambled eggs or baked beans.

Ideas for healthy snacks

Remember, something on toast or bread can be just as nutritious as a cooked meal.

Sandwiches	easy to prepare and a good way of providing a simple but well-balanced meal or snack. For variety you can try using different breads like: <ul style="list-style-type: none"> • pitta • rye • wholemeal • white • granary • rolls • French sticks 	
Fillings	<ul style="list-style-type: none"> • tuna with mayonnaise and sweetcorn • cheese with chutney, salad or yeast extract chopped egg, grated cheese and mayonnaise • tinned fish for example, sardines, pilchards, salmon with cucumber 	<ul style="list-style-type: none"> • grilled bacon, lettuce, sliced tomato and mayonnaise • peanut butter and mashed banana • cottage cheese or cream cheese flavoured with pineapple chunks, cucumber, spring onions, red pepper or grated apple • sliced cold meat with pickle and salad
Snacks on toast	<ul style="list-style-type: none"> • baked beans with grated cheese • melted cheese and sliced tomato spaghetti, ravioli with grated cheese • marmite, jam, marmalade, peanut butter, humus 	<ul style="list-style-type: none"> • mashed banana • sardines or pilchard • mashed avocado • scrambled or poached egg

Recipes

Cooking is a useful skill to have and can make it easier to manage your diet. Try these ideas:

Spicy Vegetable Couscous Serves 4 to 6

Ingredients

1 small onion (chopped)	350ml vegetable stock
1 clove of garlic (crushed)	250g couscous
1 tsp curry powder	250g courgette
1 tbsp tomato puree	250g sweetcorn and cooked peas
1 tbsp olive oil	1 red pepper (diced)
1 tbsp chopped parsley	25ml white wine vinegar (optional)
50ml olive oil (optional)	

Method

1. Heat oil in a large saucepan and add chopped onion and garlic and cook for a few minutes.
2. Add curry powder and tomato puree, stir into onion mix and continue to cook over a low heat for a few minutes.
3. Add the couscous and vegetable stock and bring to the boil.
4. Add all the vegetables (pepper, sweetcorn and peas).
5. Remove from the heat and leave to cool. All liquid should be absorbed.
6. Once cooled fluff to separate the grains and mix in the chopped parsley.
7. Mix the olive oil and vinegar (if using) and add to the couscous.
8. Optional additions: mix in cooked chicken or cooked prawns once chilled.

Nigerian Pepper Eggs on Toast

Ingredients

2 eggs	1/4 scotch bonnet pepper (finely chopped)
1 large tomato	2 tbsp of diced onion (finely chopped)
Pinch of salt	Tbsp of oil

Method

1. Cut the tomatoes, onions and scotch bonnet pepper into small pieces.
2. Put 2 eggs and salt into a bowl and whisk together with a spoon.
3. Pour the oil into a non-stick pan and once heated add the tomatoes, pepper and onion.
4. Add the egg and salt mixture to the pan, once the mixture starts to thicken stir gently.
5. Remove from heat once the egg is cooked and serve immediately on wholemeal toast.

Jollof Rice

Ingredients

2 cups easy cook rice	1 can of tomatoes
½ onion or 1 small onion	red pepper
½ scotch bonnet pepper	1 clove of garlic
1 tsp tomato puree	1½ chicken stock cubes
½ tsp thyme	water

Method

1. Wash the rice with water before cooking it, then put the rice and about 3 cups of water into a pot and place on high heat and cook for 10 to 15 minutes.
2. While the rice is cooking blend the tomatoes, onion, scotch bonnet pepper and red pepper until they are smooth in texture.
3. Add blended vegetables to the rice mixture and add enough water to allow the rice to complete cooking. (Note: since you will not be draining the rice, it is better to add too little water and check on it often, than to add too much).
4. Add in 1½ chicken stock cube, thyme and garlic and tomato puree for colour.
5. Allow the rice to continue cooking until the rice is soft. If it is not dry at this point, then switch the heat to low to allow it to dry the excess water without making the rice too soft.

Useful websites

British Dietetic Association (BDA) Food Facts

www.bda.uk.com/foodfacts/home

NHS Eat well page

www.nhs.uk/live-well/eat-well/

NHS Healthier Families

www.nhs.uk/healthier-families/

How do I contact my dietitian?

Hammersmith Hospital	020 3313 3048
Charing Cross	020 3311 1445
St Mary's Hospital	020 3312 6398

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How do I make a comment about my visit?

If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**). The PALS team will listen to your concerns, suggestions or queries. They are often able to help solve problems for you.

call: **020 3313 0088** email: imperial.pals@nhs.net

Or, if you need to **complain**, contact the Complaints department.

call: **020 3312 1337 / 1349** email: ICHC-tr.Complaints@nhs.net

write: Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street, London W2 1NY

Alternative formats

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Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk

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