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# Eating Well with Vasculitis

Food guidance to help overcome the side effects of Drug Treatment.

This leaflet is for individuals who have been diagnosed with vasculitis and are starting one of the standard drug treatments for vasculitis. It outlines the most common side effects of drugs used to treat vasculitis and how this can affect your nutritional intake, with suggestions on practical food changes that you can make to minimise these effects and keep in good health. It should be read in conjunction with advice you receive from your consultant, your family doctor and other health professionals involved in your care.

If your consultant has advised that vasculitis is affecting your kidneys then you may need more detailed advice from a dietitian who specialises in kidney (renal) problems. Your consultant can refer you.

## What is vasculitis and how is it treated?

Vasculitis is classed as an autoimmune disease where the body's immune system attacks the lining of the blood vessels. There are many different types of vasculitis, depending on which blood vessels are affected. Vasculitis is generally treated with a combination of immunosuppressants (cyclophosphamide) and steroids (prednisolone). An initial period on a high dose of these drugs is often required to control the effects of vasculitis. This is followed by a gradual reduction to maintenance amounts, or switching to drugs which have less serious side-effects. Long-term drug treatment is often necessary and may last anything from 2 years to much longer. Although the drugs usually work to reduce the symptoms of vasculitis, for many people the side-effects of the treatment can be as distressing as the disease itself.

## What are the side-effects of drugs used to treat vasculitis?

### Immunosuppressants

Cyclophosphamide, Mycophenolate Mofetil (MMF) and Azathioprine are immunosuppressants and can help to control vasculitis, but they also lower your ability to fight infection. At worst, this can make you more prone to serious infections like urinary tract and chest infections. Other side-effects can be loss of appetite, feeling sick or nauseous, taste changes and as your immune response is reduced some people may be more susceptible to food poisoning. Remember that these side-effects are usually temporary and should improve when your treatment is completed.

### Steroids

Steroids, such as Prednisolone, can also help to control vasculitis. Steroids may also boost your appetite and cause the level of fats and sugar in the blood to rise. This can lead to weight gain and increase the risk of developing type 2 diabetes and heart disease. Long-term use of steroids can cause changes to your body shape, for example filling out of cheeks and tummy and thinning of legs.

A further side-effect of this steroid treatment is osteoporosis which causes bones to become more fragile. (Again, this should improve when your treatment is completed- I am not sure this is correct as osteoporosis treatment can halt progression but rarely will reverse osteoporosis)

Making a few practical changes to what you eat may help you feel better, maintain your weight and minimise these side-effects.

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If you think that you are suffering from a side-effect of one of your tablets it is important NOT to stop taking it. Speak to your doctor who may be able to prescribe something to help or may be able to change that tablet for one which will suit you better.

### Can a healthy diet prevent me getting infections?

No specific food or group of foods will prevent or cure serious infections though if you are generally well nourished any infections to do get may be less severe and you may recover from them more quickly. The key is to follow a balanced diet. Don't delay getting advice from your doctor if you think you may have an infection.

### Am I at more risk of food poisoning because I am on drug treatment?

Storing, preparing and serving food safely are important to minimize the risk of food poisoning for everyone, but is especially important if your immune system is low as a result of drug treatment. Follow the advice below.

- Wash your hands thoroughly with warm water and soap and wash utensils and work surfaces before touching any food, to ensure that they are all clean.
- Ensure all meat, poultry, fish and eggs are well-cooked before eating.
- Do not use and eat eggs that were cracked before use.
- Wash all fruit, vegetables and salads thoroughly before use and this includes 'ready to use' bags of salad and salad vegetables
- Make sure all dairy produce such as milk and cheese are made from pasteurised milk. Be careful when shopping at a farmer's market as some products may be made with unpasteurised milk.
- Avoid soft cheeses made from unpasteurised milk like Feta, Brie, Camembert and blue vein cheeses. Instead have hard cheese or soft cheeses that are made from pasteurised milk.
- Choose canned pâté or meat spreads instead of refrigerated pâtés or meat spreads which may be unpasteurised.
- Always cook food according to the manufacturers' instructions.
- Ensure re-heated foods are piping hot throughout.
- Never re-heat food more than once.
- Leave cooked food at room temperature for a maximum of 2 hours.
- Store cooked food in the fridge (preferably below 5°C) and do not use it if it has been stored for more than 24 hours. Cooked food may be kept for longer in the freezer.
- Do not eat mouldy foods, and ensure foods are eaten within their use-by date.
- Store cooked and raw food in separate containers. Keep uncooked foods, especially meat and fish, below cooked/ready-to-eat foods in the fridge

Drinking water in the UK is generally safe to use. If you have any concerns boil water for at least a minute then store the water in clean containers in the fridge and use within 24 hours.

More advice on food safety can be found at <https://www.food.gov.uk>

### My appetite is poor and I'm losing weight – what can I eat?

You may lose weight in the early stages of treatment for vasculitis as the result of having a poor appetite or feeling sick. Even if you are overweight, this weight loss can be due to muscle rather than fat loss, which may make you feel weak and tired. Muscle loss is not a healthy weight loss so try to maintain your weight by eating smaller meals more often, and choosing foods and drinks that provide energy in small amounts. Taking some regular exercise can help maintain your muscle strength. Even simple exercises that you can do while watching TV or walking around the house will help.

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## Food Ideas to increase your energy (calorie) intake up and keep you well nourished.

Many people find that if they manage even a very small breakfast they often eat better for the rest of the day.

- Eat little and often. Try to have something to eat or drink every 2-3 hours.
- Have dry foods like a biscuit, crackers, or toast first thing in the morning as this can help settle nausea
- Swap your normal teas and coffees for hot milky drinks such as lattes, hot-chocolate or milkshakes and always use full-fat milk to increase energy intake.
- Drink between meals, rather than with meals to prevent feeling full too quickly at mealtimes.
- Add extra calories by having extra snacks like crackers and cheese, scones with jam or iced sponge fingers.
- If you are feeling sick cold food is often better tolerated so have foods such as sandwiches or salads with meat, tuna, egg or cheese followed by a mousse, yoghurt or milk pudding. Try meals prepared in advance which can be heated in the microwave if cooking smells affect your appetite or if cooking is simply too exhausting.
- To make preparing meals simpler try using packets, cans and mixes, for example:
  - meats: vacuum packed or canned
  - fish in sauce: boil in the bag or fish in crumbs
  - vegetables: frozen are just as nutritious as fresh. Try steam in the bag varieties
  - potatoes: instant or frozen mashed, microwave/oven chips, croquettes, wedges
  - instant desserts such as Angel Delight or Instant Whip
  - individual pots of custard, rice pudding, trifle, mousse, yogurt or jelly
  - frozen fruit with ice cream
  - canned fruit or fruit in pots with cream, custard or evaporated milk.
- Aim for about 1.5-2 litres (3-4 pints) of fluid a day. Not taking enough fluids can lead to problems with dehydration and constipation. However this fluid is not all water! Tea, coffee, milk, fruit juice or squash, gravy and soup all count towards your fluid intake.
- Avoid 'low-fat', 'diet', 'reduced-sugar' or 'reduced-calorie' foods for now.

## Don't forget your vitamins!

It is still important to try and eat some fruit and vegetables with your meals when your appetite is poor. Here are some suggestions to help you have more fruit and vegetables.

- A small glass of blackcurrant juice, vitamin C containing squash or fresh fruit juice.
- Chopped banana or dried fruit with cereal.
- Tomato, apple, grapes or dried fruit with cheese as a snack.
- Canned or fresh fruit as part of a pudding.
- Vegetable soup with added croutons for extra calories.
- Salad with guacamole or salad cream as part of a sandwich or roll filling.
- A portion of vegetables with sauce at main meals.

## Keep a few meals in your cupboard!

It is handy to have a store of basic foods in case it is difficult to get to the shops. Some useful essentials include:

- milk: long-life, dried or evaporated
- canned meat and fish
- starchy foods: crackers, biscuits, breakfast cereals, spaghetti, pasta, rice, instant mashed potato
- fruit: canned or dried
- vegetables: instant potato, beans, lentils, carrots, peas, tomato or sweetcorn
- puddings: canned or packets of instant milk pudding, sponge pudding
- drinks: fruit squash, long-life fruit juice, drinking chocolate or malted milk drinks like Horlicks or Ovaltine
- if you have a freezer, keep a small store of frozen foods such as prepared meals, meat, chicken, fish, fish fingers, vegetables, soup, fruits and ice cream.

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### What about ready meals?

If you are not up to cooking it is good to keep a variety of ready meals in your fridge or freezer as a standby. However, if you find shopping, preparing and cooking meals is a long term issue to your health then you may want to try homemade-style ready meals as a meal delivery service. They often cater for specialist diets including those requiring soft or puréed diets.

- Wiltshire Farm Foods  
Tel: 0800 773 773  
www.wiltshirefarmfoods.com
- Oakhouse Foods  
Tel: 0845 643 2009  
www.oakhousefoods.co.uk
- Check Meals on Wheels and other contacts through your local council.

### Food tastes different – why is this and what can I do?

#### Food Ideas

Try to make food and drinks that you enjoy and that look and smell good. Ignore food and drinks that have lost their appeal, then try them again after a few weeks. Experiment with different flavours, textures and temperatures – you may find that cold foods are more palatable.

- Adding herbs or spices to cooking may improve taste. However, be careful with spices if you have a sore mouth.
- Flavour can be added by using readymade marinades, fruit juices like lemon or pineapple, vinegar, herbs or seasoning. Try different herbs, spices and flavourings to find what you like and what works well for you.
- - For red meats, try roasting meat with strong herbs like rosemary, thyme, oregano and mint. Dishes that use minced or diced meat work well with spices and roots like garlic, ginger or even cinnamon and nutmeg.
- - Poultry works well cooked with garlic, tarragon, basil, lemon juice or chilli.
- - Fish varies a lot in flavour and can be cooked in a many ways. Smoked fish tends to be very flavourful naturally, while other fish take on flavours well. Try steaming fish with dill and peppercorns, baking it with lime and parsley or add it to a stir-fry with sesame oil and coriander.
- - Vegetarian alternatives such as tofu or Quorn, and vegetable-based dishes take on flavours very well. Add vegetables with a strong flavour such as celery, onions and tomatoes.
- Mushrooms are a natural flavour enhancer and can be added to many casserole meals or pasta dishes to add flavour

Some people experience taste changes as a side-effect of new drug treatment. Try the following ideas to help keep your food enjoyable and your intake up. It is important to try to keep eating even though food may not taste the same.

- Pickles, chutney, BBQ sauce, horseradish, mustard, mayonnaise or salad dressings can also help to improve flavour.
- Tart/sharp foods and drinks such as oranges, grapefruit, boiled sweets, mints and ice-cold fizzy drinks can be refreshing.
- If foods have a metallic taste, using plastic cutlery instead of metal may help.
- If you don't like tea or coffee, try peppermint or fruit teas instead, or try hot-chocolate or malted milk drinks like Horlicks or Ovaltine.
- Try to keep your mouth clean and fresh, especially before and after your meals.
  - Clean your teeth with fluoride tooth paste and a soft toothbrush at least twice a day or after every meal to avoid bad tastes in the mouth.
  - Clean your tongue to prevent it becoming 'coated'. Dissolve one teaspoonful of bicarbonate of soda in a pint of warm water and use with a small soft or baby toothbrush.

Ulcers or thrush (white patches and a heavily coated tongue) can affect your taste. These are easily treated with medication. Speak to your doctor or nurse if you are worried.

## I'm gaining weight – what can I do?

First of all check if you are a healthy weight for your height. This can be done at your GP surgery or local pharmacy, or you can do it yourself by following the steps at <https://www.nhs.uk/live-well/healthy-weight/>

Weight gain can be a side-effect of your steroid treatment. It is important to remember that this treatment often starts on a higher dose and then reduces as your symptoms improve and you feel better. You will hopefully reduce (or stop) the steroid dose to the lowest possible dose to keep you symptom free.

Making and keeping to a few small changes to your daily diet and activity can help you keep to a healthy weight.

Food ideas for you to try to help keep a healthy weight are listed below.

- Try a wholegrain breakfast cereal such as porridge, Bran Flakes, Shredded Wheat, Weetabix or similar, with no added sugar rather than a sugar coated cereal.
  - Have semi-skimmed or skimmed milk or natural low-fat yoghurt with your cereal or porridge rather than full-fat milk.
  - Have fresh or dried fruit with porridge or cereal.
  - Fill up with homemade soup made with vegetables and pulses and wholegrain varieties of bread rather than white.
  - Cut down on cheese or meat fillings in sandwiches by adding extra salad or use lower-fat fillings such as canned tuna, salmon or sliced chicken or turkey breast.
  - Try adding tomatoes, onions, cucumber or sweetcorn to sandwiches for example tuna salad with reduced fat mayonnaise on wholemeal bread.
  - Try tomato or vegetable-based sauces on your pasta, meat or fish dishes rather than creamy or cheese sauces.
  - Mash potatoes with a dash of olive oil or skimmed milk instead of butter or try mashing vegetables like parsnip, sweet potato or turnip with your potatoes.
  - Choose leaner cuts of meat, for example swap streaky bacon for back bacon and remove visible fat where possible.
  - Grill, bake or steam your food instead of frying.
  - Reduce sweet snacks like cakes and chocolate to occasional treats rather than everyday treats.
  - If you're out for coffee choose 'skinny' coffee made with skimmed or semi-skimmed milk or have a cappuccino rather than a hot chocolate.
  - Try squash with no-added-sugars rather than full-sugar squash.
  - Drink water – add flavour with fresh lemon or lime slices.
- Keep within the recommended alcohol limits.  
- This is that you should have no more than 14 units\* of alcohol per week for both men and -Try and have two or three alcohol free days each week.

A unit of alcohol is the amount of any alcoholic drink that contains approximately 10g of alcohol.

As a guide the following shows the units in different drinks

Type of drink	Number of alcohol units
Single small shot of spirits * (25ml, ABV 40%)	1 unit
Small glass of red/white/rosé wine (125ml, ABV 12%)	1.5 units
Bottle of lager/beer/cider (330ml, ABV 5%)	1.7 units
Can of lager/beer/cider (440ml, ABV 5.5%)	2 units
Standard glass of red/white/rosé wine (175ml, ABV 12%)	2.1 units
Pint of higher-strength lager/beer/cider (ABV 5.2%)	3 units

More information on alcohol intake can be found at

<https://www.nhs.uk/live-well/alcohol-support/calculating-alcohol-units>

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### What can I eat to keep my bones healthy?

Long-term steroid treatment can lead to developing osteoporosis. This causes your bones to become less dense, weaker and more likely to break. You can help your bone strength by:

- having a healthy diet with enough foods containing calcium and vitamin D. Vitamin D is necessary so that your body can absorb the calcium in your diet.
- taking bone strengthening drugs to counteract the effects of the steroids. Your doctor should prescribe these for you
- taking regular exercise
- stopping smoking
- keeping within sensible alcohol limits – a maximum 14 units of alcohol per week for both men and women with two or three alcohol free days each week.

Try to have 3-4 servings of the following calcium-rich foods each day including dairy foods as these are the best sources of calcium.

200ml milk (1/3 pint)

150g carton yogurt

30g (1oz) hard cheese

If you don't eat dairy foods look out for calcium-enriched soya or plant based milks and yogurt or try alternative non-dairy sources such as tofu (soya bean curd) salmon, sardines (where you eat the small bones), cabbage, pulses and oranges.

Other foods which contain less calcium, but still add to the calcium in your diet include bread, fortified breakfast cereals, baked beans and green leafy vegetables such as broccoli and kale.

Vitamin D helps your body to absorb calcium. The best food sources are oily fish such as salmon, sardines and mackerel, eggs, fortified margarine and spreads and fortified breakfast cereals. However, most vitamin D is made in the skin with help from sunlight.

Keep up your activity level. To help keep a healthy weight try walking, dancing, gardening or some exercise that you enjoy. Aim to do 30 minutes of activity 5 times per week.

### Where can I get further help?

The information contained in this leaflet is general advice, designed to help people with vasculitis who are on commonly used drug treatments. If your condition is more complex you may need very specific dietary advice. Ask your doctor to refer you to a dietitian.

The Patient Support Centre on The Lauren Currie Twilight Foundation website offers the latest in Vasculitis support and guidance. It also offers support on anxiety, relaxation, diets, nutrition and Vasculitis TV which features guidance media and webcasts: [www.thelaurencurrietwilightfoundation.org](http://www.thelaurencurrietwilightfoundation.org)

If you are taking immunosuppressants or steroids you may be advised to keep covered up in sunlight or wear total sun block and therefore need to take bone strengthening drugs. Ask your doctor or pharmacist for more information.

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