



Eating Well with Vasculitis

Food guidance to help overcome the side effects of Drug Treatment

Eating Well with Vasculitis

Food guidance to help overcome the side effects of Drug Treatment

Who is this leaflet for?

This leaflet is for individuals who are starting one of the standard drug treatments for vasculitis. It outlines the most common side effects of drugs used to treat vasculitis and suggests 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 bad as the disease itself.

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

Immunosuppressants

Cyclophosphamide, Mycophenolate Mofetil (MMF) and Azothioprine 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 and chest infections. Other side-effects can be loss of appetite, feeling sick or nauseous, taste changes and some people may be more prone 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 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 drug treatment is **osteoporosis** which makes bones become more fragile. Again, this should improve when your treatment is completed.

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

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 but if you are generally well nourished any infections 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, 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.
- Do not eat eggs that were cracked before use.
- Choose canned pâté or meat spreads instead of refrigerated pâtés or meat spreads which may be unpasteurised.
- Make sure all dairy produce such as milk and cheese are pasteurised.
- 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.
- Always cook food according to its 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.
- Wash all fruit, vegetables and salads thoroughly.
- 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.

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 due to 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 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.

Food Ideas to keep your food intake up and keep you well nourished.

- 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.
- Many people find that if they manage even a very small breakfast they often eat better for the rest of the day.
- Swap your normal teas and coffees for hot milky drinks such as lattes, hot-chocolate or milkshakes and always use full-fat milk.
- Drink between meals, rather than with meals to prevent feeling full quickly at mealtimes.
- Add extra calories by having extra snacks like crackers and cheese, scones with jam or iced sponge fingers.
- If you feel sick, have cold food and drinks 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 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
 - 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 or jelly
 - frozen fruit with ice cream
 - canned fruit with cream, custard or evaporated milk.
- Aim for about 1.5-2litres (3pints) of fluid a day. Not taking enough fluids can lead to problems with dehydration and constipation.
- Avoid 'low-fat', 'diet', 'reduced-sugar' or 'reduced-calorie' foods for now.

If you normally follow a special diet, for example if you have raised cholesterol or diabetes please discuss this with your dietitian.

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
- 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.

What about readymeals?

If you are not up to cooking or want to have homemade-style readymeals as a standby, you may want to try 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?

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.

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.

- 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 <http://www.nhs.uk/Livewell/healthy-living/Pages/height-weight-chart.aspx>.

Weight gain can be a side-effect of your steroid treatment. 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 or shredded wholegrain wheat cereal, 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 instead of sugar.
- Fill up with homemade soup 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 or fruit to sandwiches rather than mayonnaise, for example tuna salad sandwich 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 olive oil or skimmed milk instead of butter or try mashing vegetables like parsnip 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.
 - No more than three to four units of alcohol per day for men.
 - No more than two to three units per day for women.
 - One or two alcohol free days each week.

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.

What can I eat to keep my bones healthy?

Long-term steroid treatment can lead to osteoporosis. This causes your bones to become 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
- 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 –three to four units of alcohol per day for men and two to three units per day for women with one or two alcohol free days each week.
- try to have 3-4 servings of the following calcium-rich foods each day as these are the best sources of calcium: 200mls/¹/₃pint milk, small carton of yoghurt, 30g/1oz of hard cheese. If you don't eat dairy foods look out for calcium-enriched soya versions or try alternative non-dairy sources such as salmon, sardines, cabbage, beans and some nuts.

Other foods which contain less calcium but still add to the calcium in your diet include bread, cereals, nuts, fish such as sardines and pilchards where you eat the bones, baked beans and green leafy vegetables such as broccoli and cabbage.

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.

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.

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

References

Chan, M. & Luqmani, R (2009) Pharmacotherapy of vasculitis. *Expert Opinion on Pharmacotherapy*. 10(8). p.1273-1289.

Dietitians of Canada. Immune System background. 2011 *Practice-based Evidence in Nutrition* [Online]. Available only by subscription from: <http://www.pennutrition.com>. [Accessed 21/05/13].

Electronic Medicines Compendium [Online] Available from: <http://www.medicines.org.uk/emc/medicine/26755/SPC/Prednisolone> [Accessed 21/5/13].

Electronic Medicines Compendium [Online] Available from: <http://www.medicines.org.uk/emc/medicine/10550/SPC/Cyclophosphamide> [Accessed 21/5/13].

Herlyn, K; Hellmich, B.; Seo, P.; Merkel, P.A. (2010) Patient reported outcome assessment in vasculitis may provide important data and a unique perspective. *Arthritis Care and Research*. 62(11). p.1639-1645.

Royal College of Physicians; National Osteoporosis Society; The Bone and Tooth Society (2002). Glucocorticoid-induced osteoporosis A concise guide to prevention and treatment [Online] Available from: <https://www.nos.org.uk/NetCommunity/Document.Doc?id=423> [Accessed 31/5/13].

Sharma, P.; Sharma, S.; Baltaro, R.; Hurley, J. (2011) Systemic vasculitis. *American Family Physician*, 83(5). p.556-565.

Terai, H. & Shimahara, M. (2005) Atrophic tongue associated with Candida. *Journal of Oral Pathology & Medicine*. 34(7). p.397-400.

Thorpe, C.T.; DeVellis, R.F.; Blalock, S.J.; Hogan, S.L.; Lewis, M.A.; DeVellis, B.M. (2008) Patient perceptions about illness self-management in ANCA-associated small vessel vasculitis. *Rheumatology*. 47(6). p.881-886.

Walsh, M.; Mukhtyar, C.; Mahr, A.; Herlyn, K.; Luqmani, R.; Merkel, P.A.; Jayne D.R. (2011) Health-related quality of life in patients with newly diagnosed antineutrophil cytoplasmic antibody-associated vasculitis. *Arthritis Care and Research*. 63(7). p.1055-1061.

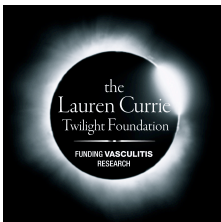
This information was produced for Nutrition and Diet Resources UK (NDR-UK) with the kind support of dietitians and related health and care professionals. At the time of publication the information contained within the resource was, to the best of our knowledge, correct and up-to-date. Always consult a suitably qualified dietitian and/or your GP on health problems. NDR-UK cannot be held responsible for how clients/patients interpret and use the information within this resource. Visit www.ndr-uk.org for more information and to contact the team on the development and evidence supporting this resource.



© NDR-UK Ref: 1008, First published: 08/13
Next review: 08/16

DR-UK – the UK’s practitioner-led nutrition and diet resource provider.
Registered charity number SC041043, company number SC364677.

Funded by::



www.thelaurencurrietwilightfoundation.org