



Alström Global Community Wellness Club Food, Fitness and Healthy Habits

**Webinar
28th April 2022**

Top Tips for enjoying a Healthy Lifestyle

This webinar brought together, Dr Richard Paisey, Alström Syndrome clinical expert and Marina Valenti, Mom, and expert by experience from AS Italy Association, who gave their viewpoints about leading a healthy lifestyle to the Alström global community.



Dr Richard Paisey



Marina and Valentina

Q1. Can you prevent diabetes with a healthy diet and exercise?

Dr Richard Paisey: Published studies over a 10-year period, from Finland, USA, UK, and China have found that a healthy lifestyle can reduce by half the chance of developing diabetes in adults at risk from being overweight and borderline high blood glucose levels(pre-diabetes) [1,2].

In Alström Syndrome the diabetes is linked with the genetic change causing extreme resistance to insulin. Lifestyle has just as important a part to play, as exercise and healthy eating will delay the onset of diabetes. Two studies comparing Canadian

and Italian people with Alström syndrome from their early years up to reaching their twenties, looking at their lifestyle, culture, and diet, found that Canadians were very overweight by their mid-teens and had diabetes. Whereas the Italians who were studied had significantly less individuals who went onto develop diabetes, they were slimmer, and no insulin was needed [3,4].

Q2. What are the advantages and disadvantages of medicines which control appetite?

Dr Richard Paisey: There are three types of medicines which control appetite:

1. Medicines that mimic the bodies appetite control
2. Medicines that don't allow the absorption of fat
3. Medicines that affect the brain and hormones to make people feel full.

Over the years, many of these drugs have had unacceptable side effects and have all been withdrawn.

One drug which has been established and is now used is semaglutide. It works to mimic a hormone from the bowel which sends a message to the brain to say you are full. This hormone is reduced in type 2 diabetes, including those with Alström syndrome.

Some people with AS have started on this drug and once the initial three months of side effects subsides, the results appear to have been positive [5].

"It is the first time in my life I have ever felt full", experience of adult with AS who is taking the drug semaglutide.

Note: This therapy is not yet licensed for under 18-year-olds.

Q3. Is metformin a good drug to take for diabetes for a person with Alström?

Dr Richard Paisey: Yes, it has been recognised to help people control their sugars for over 50 years.

It stops the liver producing too much sugar, so that diabetes improves. It won't stop the diabetes or cause weight loss.

Note: If you are very unwell, metformin must be stopped as in this circumstance it can cause too much acid in the blood.

Q4. Is a keto diet recommended if you have diabetes and Alström?

Dr Richard Paisey: The ketogenic diet is a very low carbohydrate, high fat diet that shares many similarities with the Atkins and low carb diets.

It involves drastically reducing carbohydrate intake and replacing it with fat. This reduction in carbs puts your body into a metabolic state called ketosis.

Ketosis is a metabolic state in which your body breaks down fat to ketones which can fuel the brain heart and muscles instead of sugar. Following a ketogenic diet is the most effective way to enter ketosis. Generally, this involves limiting carb consumption and filling up on fats and protein, such as meat, fish, eggs, nuts, and healthy oils.

It is a way to lose weight quickly, and can control type 2 diabetes. The longest studies have lasted up to 5 years, and more studies are needed [6].

Yo-yo diets aren't healthy and instead consider leading a healthy diet, reducing the size of your meals, avoiding junk food, and eating wholemeal, bread, pasta, and rice maybe a more sustainable way to eat healthily. Leading a healthy lifestyle is a long-term plan, developing healthy habits works better than a short-term fix [7].

Q5. Is a cross-fit or high intensity training recommended if you have Alström?

Dr Richard Paisey: High-intensity interval training (HIIT) is a type of workout that combines short bursts of intense exercise with periods of rest or lower intensity exercise.

Alongside a healthy diet, cross fit training and HIT training can be a good way to feel well. It is also as good as other exercise such as walking.

It can be a good method as you don't need expensive equipment or need to go to the gym-try press ups, sit ups and running on the spot or a static bicycle in your own home!!

Q6. How common is extreme insulin resistance in people with Alström?

Dr Richard Paisey: It is a key marker for diagnosing Alström. It shows the genetic effect of the syndrome which slows the flow of glucose into cells.

Q7. What is the impact of cholesterol?

Dr Richard Paisey: Cholesterol is very important to consider.

Many people affected by Alström syndrome have high blood cholesterol and triglyceride levels. In combination with diabetes and kidney disturbance this has been shown to cause hardening of the arteries, even heart attacks in those who are 30 to 40 years old. Nowadays with good treatment/prevention of these conditions from an early age this can be prevented.

We are now diagnosing Alström earlier, so we can treat with statins and adopt a healthy lifestyle to try to prevent hardening of the arteries[8] .

Q8. What are your top tips for a healthy lifestyle?

Bite size Top Tips:

1. Keep active
2. Keep your weight down
3. Avoid fatty foods, such as junk food
4. Don't drink sugary drinks

Marina shared her top tips for encouraging healthy eating for toddlers

- Try to make sure the food is as interesting as possible
- Keep to strict rules as a healthy diet is so important
- Ensure the people around your child also know why this is important
- Get them involved in the preparation and cooking, handling different textures, and trying new tastes.

In the UK, there is the Foodie Active Friends Clubs, where children and young people prepare and cook together. It is a great way to try new foods and handle different textures and tastes.



- Use high quality dark chocolate to dip fruit into
- Wrap the fruit in brightly coloured paper to unwrap, especially at parties so the children don't feel left out and take alternatives that they will like instead of the sugary sweets and cakes.

Top Tips for healthy eating

1. Reduce carbohydrates and replace with wholemeal options such as pasta, bread and rice.
2. Nuts are good – but avoid salted, roasted nuts or additives such as extras like Cajun as these come with extra fats and salts.
3. Cut down on processed food and junk food.

4. Fruit and vegetables are mostly slow release and un-processed, they contribute to a healthy balanced diet, increase vitamin intake and feeling of fullness, and increases fibre intake.
5. Sugar, including sugary breakfast cereals and sugary drinks are not recommended. These should be avoided and can give an excessive insulin release.
6. Use natural sweeteners, like honey and try cake recipes using root vegetables like beetroot, carrot or parsnip.

Further Information

There are more top tips, healthy recipes, and exercises on the ASUK Wellbeing Cub area of the website:

<http://www.alstrom.org.uk/stay-fit-stay-healthy-stay-happy/>

Published research papers can all be found on the ASUK website:

<http://www.alstrom.org.uk/research-papers/>

Thank you

Thank you to everyone who joined the session and particularly to Dr Richard Paisey, Marina and Valentina who shared a short video of her extraordinary roller blading and other activities about how she stays healthy.

We're always pleased to share quotes from attendees:

“Dr Paisey explanations were extremely interesting and puts lots of the pieces of the puzzle together, because his explanations are very simple”

“Thank you for the opportunity to all get together, it has been so interesting”

Be part of the Alström Global community, join us for our next session, they take place on the last Thursday of the month.

Get in touch to share with us your ideas for future webinars or if you would like to talk about a particular topic. We would love to hear from you!

Contact Catherine by email catherine.lewis@alstrom.org.uk

...and don't forget to complete the Alström Global Patient Registry

<http://www.alstrom.org.uk/patient-registry/>

Linked published papers:

1. Lindström J, Ilanne-Parikka P, Peltonen M, Aunola S, Eriksson JG, Hemiö K, et al. Sustained reduction in the incidence of type 2 diabetes by lifestyle intervention: follow-up of the Finnish Diabetes Prevention Study. *The Lancet*. 2006;368:1673–9.
2. Diabetes Prevention Program Resea. 10-year follow-up of diabetes incidence and weight loss in the Diabetes Prevention Program Outcomes Study. *The Lancet*. 2009;374:1677–86.
3. Mokashi A, Cummings EA. Presentation and course of diabetes in children and adolescents with Alstrom syndrome. *Pediatr Diabetes*. 2011;12:270–5.
4. Bettini V, Maffei P, Pagano C, Romano S, Milan G, Favaretto F, et al. The progression from obesity to type 2 diabetes in Alström syndrome. *Pediatr Diabetes*. 2012;13:59–67.
5. wilding. Wilding JPH, Batterham RL, Calanna S, et al. Once-Weekly Semaglutide in adults with overweight or obesity. *N Engl J Med* 2021;384:989–1002. *N Engl J Med* 2021. 2021;384:989-1002.
6. Unwin D, Khalid AA, Unwin J, Crocombe D, Delon C, Martyn K, et al. Insights from a general practice service evaluation supporting a lower carbohydrate diet in patients with type 2 diabetes mellitus and prediabetes: a secondary analysis of routine clinic data including HbA1c, weight and prescribing over 6 years. *BMJ Nutr Prev Health*. 2020;3:285–94.
7. Paisey R, Daniels C, Howitt W, Greatorex D, Campbell C, Paisey C, et al. Body weight, diabetes incidence vascular events and survival 15 years after very low calorie diet in community medical clinics in the UK. *BMJ Nutr Prev Health*. 2022;e000363.
8. Paisey RB, Smith J, Carey C, Barrett T, Campbell F, Maffei P, et al. Duration of Diabetes Predicts Aortic Pulse Wave Velocity and Vascular Events in Alström Syndrome. *J Clin Endocrinol Metab*. 2015;100:E1116-1124.

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