

Understanding Alström Syndrome

One Day Course



Overview

Alström Syndrome is a very rare and recessively inherited condition that is characterised by a number of key conditions including retinal degeneration, sensorineural hearing loss, obesity and insulin resistance, which often means late diagnosis of the condition.

Because of its complexity and rarity, many GP's and other professionals have not come across Alström Syndrome before. By raising awareness, earlier diagnosis and improved treatment should follow.

Who should come on the course?

- Anyone working in the following settings would benefit from the course.
- It is also beneficial to anyone working with people with other rare complex diseases as many of the problems encountered by Alström Syndrome patients are experienced by everyone with rare complex disorders.

Medical: GP's, Cardiology Depts, Diabetes workforce (children and adults), Renal Depts, Audiology Depts, Eye hospitals, Paediatricians, Medical training schools. **This training course has been CPD approved by the Royal College of Physicians (code 55493) and is worth 6 credits (clinical).**

Educational: Schools for blind children, VI workers in mainstream schools, VI workers in Universities, Colleges for blind people, Schools for deaf children, Colleges for deaf people

Social: Other charities e.g. Deafblind UK, Sense, RNIB, RNID, NDCS, Diabetes UK, Dilated Cardiomyopathy association etc. Deafblind workforce (dealing with both children and adults), Visual Impairment teams in social services.

Learning Outcomes

Throughout this course participants will:

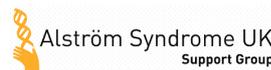
- Learn how to improve treatment of people with Alström Syndrome.
- Understand how to communicate with people who have a hearing loss and a visual impairment.
- Raise awareness and understanding of the Syndrome.
- Encourage good practice within their organisation.

Training is delivered on behalf the charity Alström Syndrome UK by HearFirst, an independent provider of disability related training.

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Course Content

- Have the opportunity to meet someone who has first hand knowledge of Alström Syndrome.
- Know the basic characteristics and additional features of Alström Syndrome.
- Understand how people with Alström Syndrome feel (and their families).
- Learn how to communicate effectively with people with dual sensory loss i.e. deafblind.
- Become familiar with good practice of education/treatment, care providers etc.
- Know what help is available and by whom. Know the use and limitations of assistive equipment and aids.
- Know the key points of the Equality Act in relation to disability.
- Have an action plan to ensure participants own actions have a positive impact on people with Alström Syndrome i.e. including how the Social Model of Disability can be applied to people with Alström Syndrome.

Booking Information

- **Organisations** - Training can be at your venue on dates to suit you for up to 15 delegates.
- **Individuals** - Individuals may want to book on one of our open courses.
- **Shorter sessions** and more informal 'talks' are also available.

Please contact either HearFirst (contact details below) or Alström Syndrome UK for further information.

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