



AT Specialist Adults's Clinic Factsheet

In October 2004 the AT Society organised an international meeting in Birmingham to highlight progress in AT research and the challenges ahead.

An international consensus emerged that chest problems in adults with AT were a major cause of ill health and sadly death. Separate studies indicated that several factors may contribute to chest problems in AT including difficulties in swallowing, breathing, muscular control, infections and a weakened immune system.

Royal Papworth Hospital was identified as the UK centre with the blend of expertise required for people with AT. The centre provides medical assessments for people aged 16 plus.

Main Aims

- To improve quality and length of life for adults with AT
- To provide a full medical assessment of the patient within the multidisciplinary team
- To provide Information on all aspects of AT based on the needs of the individual affected by AT
- To provide a written report, with recommendations for future care which is sent to the adult with AT, GP and local care team.
- To aid research into AT
- To set up a programme to assess the factors that contribute to chest problems in adults with AT

The Team at Royal Papworth Hospital

- Natasha Everett - AT Clinic Coordinator(RSSC MDT Coordinator)
- Dr Nick Oscroft - Respiratory Consultant – Clinical Lead
- Corinne Gaston - Speech & Language Therapist
- Penny Martin - Social Worker
- Jose Barros Andrade – Social Worker
- Geneticist – Professor Marc Tischkowitz (not part of the AT Service, but available on an as needed basis)
- Clare Witcombe – Dietitian
- Dr Clare Bolton – Neurologist
- Nikki Gilbert – Physiotherapist and Lorna Brown



- Occupational Therapist – Amy Chadwick

Assessments

- Blood tests
- Respiratory assessment including breathing test
- Immunological assessment
- Video fluoroscopy
- CT Scan
- Sleep study

Additional neurological investigations will be offered on your second visit which will include:

MRI brain scan
Nerve Conduction Study
Geneticist

Please do not hesitate to discuss this with the neurologist or Natasha prior or during your review.

MRI breast screening will be offered to females over 25

Radiation Risks

A high-resolution CT chest scan and video fluoroscopy are standard investigations for assessment of chest problems, a major cause of ill health and death in AT. We also know that AT is a disorder associated with increased sensitivity to radiation at levels associated with radiotherapy, rather than diagnostics.

Discussions with AT clinical experts at the international meeting in October 2004, at the Nottingham AT Clinic, with Professor Malcolm Taylor, University of Birmingham and with the AT Society have produced a consensus that a high-resolution CT chest scan and video fluoroscopy are low risk and essential to clinical assessment in AT.

The CT scan and video fluoroscopy will be assessed by our radiologists who have considerable expertise in chest problems.

The team are sensitive to concerns about radiation risks and are happy to discuss this. No examinations will be carried out without consent.

Visit

When you come to Royal Papworth Hospital, you are admitted as an inpatient. You



will stay in a private room with en-suite bathroom and flat screen TV. There is a pull-out bed in the room for a relative or carer to use. The AT Society can also arrange B&B accommodation for other relatives/carers nearby if required together with transport if needed.

Admission is on Sunday evening, and you are seen by various Doctors/Therapists during your stay at Royal Papworth. You will be discharged on Tuesday lunchtime. Appointments run throughout the year and are arranged to suit your needs. You will be called back to Royal Papworth every 1-2 years for a review.

Referral

Young people with AT or AT like conditions (ATLD) or AOA1 or AOA2 already attending the children's AT service in Nottingham, will transition to the adult AT service when they reach 16 years of age.

Adults (16 years plus) with AT or AT Like Conditions or AOA1 or AOA2 should be referred to the centre by their local GP or hospital consultant. The AT Society can contact your GP or Consultant to start the process. Referrals should be addressed to: **Dr Nick Oscroft, Adult AT Services, RSSC, Royal Papworth Hospital, Papworth Road, Cambridge Biomedical Campus, Cambridge, CB2 0AY**

You can also contact Natasha Everett – RSSC MDT Coordinator 01223 639452 or email natasha.everett1@nhs.net

If you have any queries regarding this centre or would like to arrange an appointment, please contact the AT Society 'Support Team', Kay Atkins (Head of Services) or Anne Murray (Family Support Manager) on **01582 760733** or email support@atsociety.org.uk or Natasha Everett, above.