

My name is: .....

## This is my **Hospital Passport**

**I have a rare genetic medical disorder. Please read this document.**

If I have to go to hospital this book needs to go with me – it gives hospital staff important information about me. It needs to hang on the end of my bed and a copy should be put in my notes.

- This passport belongs to me
- Please return it when I am discharged
- Nursing and medical staff please look at my passport before you interact with me.



Things you must know about me

Things that are important to me

Important notes and contact info

**Please note I have a rare genetic medical disorder:  
Ataxia Telangiectasia**

Please see [www.atsociety.org.uk/about-a-t/](http://www.atsociety.org.uk/about-a-t/) for more information or contact the National Adult A-T Service at Royal Papworth Hospital on 01223 638000 and ask for Dr Nicholas Oscroft.

# Things you must know about me

Name: .....

Likes to be known as: .....

NHS number: .....

Date of Birth: .....

Address: .....

.....

Tel No: .....

How I communicate/what language I speak: .....

.....

Family contact person, carer or other support: .....

.....

Relationship e.g. Mum, Dad, Home Manager, Support Worker: .....

.....

Address: .....

.....

Tel No: .....

My support needs and who gives me the most support: .....

.....

My carer speaks: .....

Date completed .....

by .....

Religion: .....

Religious/Spiritual needs: .....

Ethnicity: .....

GP: .....

Address: .....

.....

Tel No: .....

**Other services/professionals involved with me:  
Please copy correspondence and request advice if necessary**

National Adult Ataxia Telangiectasia Service at Royal Papworth Hospital  
Point of Contact: Care Coordinator – Natasha Everett  
email: [Natasha.everett1@nhs.net](mailto:Natasha.everett1@nhs.net), Tel: 01223 639452

Ataxia Telangiectasia Clinical Lead: Dr Nicholas Oscroft, Respiratory Consultant –  
Secretary Caroline Woodcock 01223 639803  
Out of Hours Contact for Royal Papworth is the RSSC Consultant on 01223 638000

Allergies: .....

.....

Other diagnoses: .....

.....

.....

.....

Liver: .....

Immunodeficiency: .....

Risk of choking, Dysphagia (eating, drinking and swallowing): .....

.....

Date completed .....

by .....



# Things you must know about me

Current medication: .....

.....

.....

.....

.....

## My past medical history and treatment plan: I have a rare genetic medical disorder: Ataxia Telangiectasia

Please see [www.atsociety.org.uk/about-a-t/](http://www.atsociety.org.uk/about-a-t/) for more information or contact Royal Papworth Hospital or the AT society. Due to this condition I am sensitive to ionising radiation and have a high risk for developing neoplastic lesions.

It is strongly recommended to clinicians treating people with A-T that in the event of unusual or otherwise unexplained symptoms, consideration be given at the earliest possible opportunity to the possibility of cancer being the cause, and appropriate tests carried out.

Although people with A-T are very sensitive to ionising radiation due to their underlying genetic defect, the use of tests involving ionising radiation is probably warranted where no other imaging modalities (eg ultrasound) would give satisfactory diagnostic results. However, radiotherapy and radiomimetic drugs should be avoided. Advice is available on some side effects seen in A-T children treated with some cytotoxics<sup>5</sup>.

More information is available at [www.atsociety.org.uk/for-professionals/](http://www.atsociety.org.uk/for-professionals/)

Date completed .....

by .....

# Things that are important to me

How to communicate with me: .....

.....  
.....  
.....

How I take medication: (whole tablets, crushed tablets, injections, syrup) .....

.....  
.....  
.....

How you know I am in pain: .....

.....  
.....  
.....

Moving around: (Posture in bed, walking aids) .....

.....  
.....  
.....

Personal care: (Dressing, washing, including assistive equipment etc) .....

.....  
.....  
.....

Date completed .....

by .....

# Things that are important to me

Seeing/Hearing: (Problems with sight or hearing) .....

.....

.....

How I eat: (Food cut up, pureed, risk of choking, help with eating) .....

.....

.....

How I drink: (Drink small amounts, thickened fluids) .....

.....

.....

How I keep safe: (Bed rails, help with transferring) .....

.....

.....

How I use the toilet: (Continence aids, help to get to toilet) .....

.....

.....

Sleeping: (Sleep pattern/routine) .....

.....

.....

Date completed .....

by .....

# Contacts and useful websites

## **National Adult Ataxia Telangiectasia Service at Royal Papworth Hospital**

Point of Contact: Care Coordinator – **Natasha Everett**

email: [Natasha.everett1@nhs.net](mailto:Natasha.everett1@nhs.net) / Tel: 01223 639452

Ataxia Telangiectasia Clinical Lead: **Dr Nicholas Oscroft**, Respiratory Consultant – secretary **Caroline Woodcock** 01223 639803

Royal Papworth Hospital NHS Foundation Trust

Papworth Road | Cambridge Biomedical Campus | Cambridge | CB2 0AY | 01223 638000

**AT society** – charity that supports me and my family

Contact: **Kay or Anne**

01582 760733 [kay@atsociety.org.uk](mailto:kay@atsociety.org.uk) or [anne@atsociety.org.uk](mailto:anne@atsociety.org.uk)

[www.atsociety.org.uk](http://www.atsociety.org.uk)

Please contact the National Adult A-T Service at Royal Papworth Hospital if you have any questions about the passport.

**Royal Papworth Hospital NHS Foundation Trust**

Papworth Road  
Cambridge Biomedical Campus  
Cambridge  
CB2 0AY

Tel: 01223 638000

**[www.royalpapworth.nhs.uk](http://www.royalpapworth.nhs.uk)**

**A member of Cambridge University Health Partners**

**Author ID:** Ataxia Telangiectasia Coordinator  
**Department:** Respiratory Support and Sleep Centre  
**Reprinted:** January 2022  
**Review due:** January 2024  
**Version:** 1  
**Leaflet Number:** PI 217

Large print copies and alternative language versions of this leaflet can be made available on request.