

Protocol for Children and Adults with Autism Spectrum Conditions

V1.0

May 2014

Table of Contents

1. Introduction.....	3
2. Purpose of this Policy/Procedure.....	3
3. Scope	4
4. Ownership and Responsibilities.....	4
4.1. Chief Executive.....	4
4.2. Executive Directors.....	4
4.3. Associate Medical Director/Consultants	4
4.4. Ward/Unit Managers.....	4
4.5. Members of Clinical Teams	5
4.6. Quality, Safety and Compliance Team	5
4.7. Role of Individual Staff	5
5. Standards and Practice	5
5.1. The ‘Autism Quick Guide to me’	5
5.3. The Hospital Communication Book	5
5.7. Appointments.....	6
5.12. Medical procedures.....	6
5.14. Your language.....	6
5.22. Physical examinations	7
5.33. Lights	7
5.36. Sensory overload	7
5.39. Pain.....	8
5.47. Emergency Department (ED).....	8
5.56. Training and Education	9
5.59. Partnership working	9
5.60. Flagging Alert System.....	9
5.61. Complaints.....	9
6. Dissemination and Implementation.....	9
7. Monitoring compliance and effectiveness.....	10
8. Updating and Review.....	10
9. Equality and Diversity	11
9.2. Equality Impact Assessment.....	11
Appendix 1. Governance Information	12
Appendix 2. Initial Equality Impact Assessment Form	14

1. Introduction

1.1. Autism and Autistic Spectrum Disorders (ASD) is the term that is used to describe a group of disorders, including Autism and Asperger's syndrome. The word 'spectrum' is used because the characteristics of the condition vary from one person to another. Autism is a lifelong developmental disability that first appears during infancy or childhood and affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them. Individuals with autism may also have a learning disability. Those who have Asperger's syndrome tend to have average, or above average, intelligence, but still have difficulty making sense of the world and interacting with others.

1.2. People with ASD experience three main difficulties, often known as the 'triad of impairments':

- **Social interaction** - difficulty with social relationships, often appeared distant or detached.
- **Social communication** – difficulty with understanding verbal and non – verbal communication. Body language, gestures, facial expression, tone of voice.
- **Social imagination** – difficulty with interpersonal play and imagination e.g. having a limited range of imaginative activities, possibly copied and pursued rigidly and repetitively.

In addition to this triad, repetitive behaviour patterns and resistance to change in routine are often characteristic. They may also be hyper – or hyposensitive to sound, touch, pain, lights etc.

1.3. The Autism Act (2009), Autism Strategy (2010) and the update (2014) and NICE Autism Clinical Guideline (2012) identify that a significant proportion of adults with autism across the whole spectrum experience social and economic exclusion. The condition has been noted as 'frequently overlooked by health, education and social care professionals, which in turn creates barriers to accessing the support and services needed'. The NICE guidelines offer the best practice advice on the person centred care of adults with autism. It highlights that support and care 'should take into account peoples' individual needs and preferences'. Additionally it states 'people with autism should have the opportunity to make informed decisions about their care, in partnership with healthcare professionals'. Where individuals lack capacity, decisions are made in the individual's best interests according to the statutory requirements set out through the Mental Capacity Act 2005. This Protocol sets out how the Royal Cornwall Hospital NHS Trust will meet the best practice guidelines to ensure a safe and responsive service for those with ASD.

2. Purpose of this Policy/Procedure

2.1. People with ASD have the right to the same level of health care as that provided to the general population. This care should be flexible and responsive and any diagnosis or treatment must take account of specific needs associated with the person's needs.

2.2. This Protocol has been subject to an Equalities Impact Assessment Screening and all aspects will enhance equality. In order to ensure adherence to these principles the main areas of focus will be:

- To enable staff at the acute Trust to develop a better understanding of people with ASD and to equip them to deal more effectively with the particular needs of each individual.
- To clarify for residential and other ASD staff attending the hospital with a person with ASD their supporting/caring role and the boundaries between their caring role and the nursing role of the professional hospital staff.
- Support patients, parents and carers in implementing the 'Autism Quick Guide to me'.
- To provide an opportunity for hospital staff and the dedicated Liaison Nurse to work together to develop: effective communication, training and education awareness and accessible information.

3. Scope

3.1. This protocol applies to all staff employed within Royal Cornwall Hospital Trust who has responsibility for the care of patients, or provide a service, including those with ASD.

4. Ownership and Responsibilities

4.1. Chief Executive

The Chief Executive and wider Trust Board have key roles and responsibilities to ensure the Trust meets requirements set out by statutory and regulatory authorities such as the Department of Health, Commissioners and the Care Quality Commission. The Trust's Chief Executive has overall responsibility to have processes in place to:

- Ensure that clinical staff are aware of this policy and adhere to its requirements
- Ensure that appropriate resources exist to meet the requirements of this policy

4.2 Executive Directors

The Executive Directors are responsible for ensuring that all operational managers in their area are aware of this policy, understand its requirements and support its implementation.

4.3 Associate Medical Director/Consultants

The Associate Medical Director and Consultants are responsible for ensuring legal frameworks and procedures detailed in this policy are understood and adhered to by medical staff.

4.4. Ward/Unit Managers

Ward/Unit Managers are responsible for implementing the policy and ensuring that relevant assessment tools are readily available to allow staff to carry out the duties prescribed in this policy.

4.5 Members of Clinical Teams

Clinical team members have responsibility to comply with the requirements of this and associated policies and have a legal duty to adhere to the Act and Code when working with, or caring for, adults who may lack capacity to make decisions for themselves.

4.6. Quality, Safety and Compliance Team

The Quality, Safety and Compliance Team are responsible for informing the Care Quality Commission (CQC) of all DOLS applications and outcomes. This is a statutory requirement.

4.7 Role of Individual Staff

Any member of staff, including volunteers that come into contact with a patient with ASD must be aware of what this means, how they should be treated and from where they can find more information and help.

Clinical staff who may be involved in the assessment, diagnosis, treatment or care of patients with ASD must be able to identify the fact and adapt their approach accordingly. Care and treatment plans must be drawn up with the ASD in mind so that reasonable adjustments are planned and delivered.

Clinical staff must also know how to get help and advice, and do so as necessary. Staff have been advised to contact the Acute Liaison Nurse for further information on 'easy read' patient information.

Clinical staff should always act as the patients advocate ensuring that they are given information about their condition and/or treatment in a way that they can understand in order to make decisions within the limits of their capacity. It is important that clinical staff acknowledge that family members/carers understand the ASD best and work in partnership with them to ensure that the communication needs of the individual are met.

5. Standards and Practice

5.1. The 'Autism Quick Guide to me'

5.2. The Royal Cornwall Hospital is dedicated to the development & introduction of the Autism Quick Guide to me' for patients with ASD. This is a patient held record that accompanies the patient throughout their journey in hospital. It provides key information for staff such as communication needs, Social needs and behavioural patterns. This document helps patients and carers highlight specific support needs before and during admission. Clinical staff are then able to better assess, plan, manage & evaluate care and treatment using a much more person-centred approach.

5.3. The Hospital Communication Book

5.4. The Hospital Communication Book has been available to all staff. This resource is available on each ward, clinic & department for all staff to use. This is an excellent resource that contains useful information and advice and a range of communication techniques and strategies such as signs & symbols on how to communicate effectively with people who have difficulties with communication.

5.5. Accessible information is available when required about procedures, services and treatment. The ALN team also have iPads that are used on an individual basis to aid communication with a variety of applications available. To ensure that equal and effective individualised communication is achieved to support positive health outcomes.

5.6. Individual 'reasonable adjustments' are made when required. To ensure the Trust complies with the Equality Act (2010). Some examples top tips for acute hospital staff:

5.7. Appointments

5.8. Try to give the patient with an ASD the first or last appointment of the day. People with an ASD find waiting around for an appointment extremely stressful.

5.9. Waiting in busy hospital corridors will increase the stress levels of an already anxious child or adult.

5.10. If possible, find a small side room the family can wait in.

5.11. Alternatively, they may prefer to wait outside or in the car and a member of staff should be identified to collect them when the health professional is ready. If the appointment is likely to be delayed, the family may wish to leave the building completely and return at a later agreed time.

5.12. Medical procedures

5.13. Always explain what you are going to do before starting any procedure or examination. If possible, show a picture of what is going to happen or use a dummy (if appropriate) to explain what you are going to do.

5.14. Your language

5.15. Use clear simple language with short sentences.

5.16. People with an ASD tend to take everything literally. Thus, if you say "It will only hurt for a minute" they will expect the pain to have gone within a minute.

5.17. Make your language concrete and avoid using idioms, irony, metaphors and words with double meanings, eg "It's raining cats and dogs out there." This could cause the patient to look outside for cats and dogs.

5.18. Give direct requests, eg "Please stand up." If you say, "Can you stand up?" this may result in the person staying seated or the answer "yes", as the person with an ASD may not understand you are asking them to do something.

5.19. Check that they have understood what you have said - some people with an ASD may speak clearly but can lack full understanding.

5.20. Avoid using body language, gestures or facial expressions without verbal instructions. These may not be understood.

5.21. Ask for the information you need. A person with an ASD may not volunteer vital information without being asked directly.

5.22. Physical examinations

5.23. These may prove very stressful to the patient and it is essential to warn them before touching them.

5.24. Explain what you are doing and why.

5.25. Enlist the parent/carers help wherever possible, especially if the patient is non-verbal or uses an alternative communication method or aid.

5.26. Response by patient

5.27. Don't be surprised if the patient doesn't make eye contact, especially if he or she is distressed. Lack of eye contact does not necessarily mean they are not listening to what you are saying.

5.28. Allow the patient extra time to process what you have said.

5.29. Don't assume that a non-verbal patient cannot understand what you are saying.

5.30. People with an autistic spectrum disorder find it difficult to understand another person's perspective. They may not understand what you intend to do, but may expect you to know what they are thinking.

5.31. People with an ASD may not understand personal space. They may invade your personal space or need more personal space than the average person.

5.32. Sensory stimuli some or all of the following may apply to your patient.

5.33. Lights

5.34. Some people with an ASD are extremely sensitive to light and can discern the flashing of fluorescent lights.

5.35. Pen lights can trigger seizures in susceptible individuals. Seizures occur in 20-30% of people with an ASD¹.

5.36. Sensory overload

5.37. It is easy for someone with an ASD to be overcome by sensory overload, for example in the hustle and bustle of an emergency department. Emergency lights and machines emit high-pitched 'whistle' sounds which can be agonising to the person with an ASD.

5.38. Whereas some might withdraw (eg put their fingers in their ears, close their eyes) others 'stim'. This means to make motions such as flapping hands, rocking or flicking fingers in order to stimulate sensation or to deal with stress. This kind of behaviour may also be calming to the individual, or aid balance and posture, so do not try and stop it unless absolutely essential.

5.39. Pain

5.40. People with an ASD can have a very high pain threshold. Even if the person does not appear to be in pain, they may, for example, have broken a bone.

5.41. They may show an unusual response to pain that could include laughter, humming, singing and removal of clothing.

5.42. Agitation and behaviour may be the only clues that the child or adult is in pain.

5.43. Injections/blood tests:

5.44. If the patient needs an injection or blood test, try and divert their attention elsewhere as before, the use of pictures or a dummy is a good idea to demonstrate what is going to happen.

5.45. People with an ASD can be either under or over sensitive to pain so that some may feel the pain acutely and be very distressed whereas others may not appear to react at all.

5.46. It is advisable to assume that the patient will feel the pain and use a local anaesthetic cream such as EMLA cream to numb the site of injection.

5.47. Emergency Department (ED)

5.48. ED is a very stressful experience for anybody, but for the person with an ASD it can be totally overwhelming. Not only is it a strange place, and at times chaotic, the sensory experience of bright lights, beeping monitors and other equipment, can completely overload their system causing a 'meltdown' or total withdrawal.

5.49. A meltdown occurs when someone becomes over stimulated, for example by noise, or too much information, or due to anxiety leading to a state of not being able to cope with any further incoming information and possible behavioural outbursts or withdrawal.

5.50. Allow the parent or carer to take control, as they will know the best way to calm the patient down. The patient may exhibit challenging behaviour and parents/carers should be allowed to calm the patient down.

5.51. Sometimes doctors and nursing staff ask relatives/carers to leave the room whilst giving emergency treatment. In treating patients with an ASD, it may be helpful to allow them to stay if possible. This can help reassure the patient, and will also allow the relatives/carers to give valuable information about the patient and their behaviour, if appropriate.

5.52. Inform the triage nurse that the patient has an autistic spectrum disorder so that they can be given a higher priority than would be normal. This is to minimise the time the patient has to wait and is a reasonable adjustment.

5.53. Allow the patient and carers to use the relatives room if it is free.

5.54. Try to limit the number of staff caring for the patient predictability helps them understand what is happening to them and to identify the roles of care providers.

5.55. Allocate a key person to the patient if possible

National Autistic Society, (last updated March 2013) available at.

<http://www.autism.org.uk/working-with/health/patients-with-autism-spectrum-disorders-guidance-for-health-professionals.aspx>

5.56. Training and Education

5.57. The Acute Liaison nurse's provide training for clinical staff on their Induction and Mandatory sessions which aims to improve the knowledge, skills and awareness of all staff who are involved in or who contribute to the patient pathway for patients with ASD. The training is coordinated by the Learning and Development Department and is aimed at all staff across the Trust such as consultants, clinicians, receptionists, bed managers, porters, Clerical staff etc.

5.58. The Safe Guarding Team also has a number of Link Staff who are the link professional for their ward/department. The link professionals have an extra level of training (level 2) and are provided with more in depth information on how to best support patients with ASD. They are the link person to provide their ward/department with new and up dated information on ASD and are invited to ASD related training courses etc.

5.59. Partnership working

Multi-agency and multi-disciplinary partnership working is essential to ensuring positive health outcomes for people with ASD. Working together with other health providers such as the Community Teams who frequently provide support and health education in the community, social care providers such as Social Workers and Home Care providers and family carers requires effective communication and information sharing which is paramount to safeguarding the individual and prevent harm. Family carers and support workers must be included in planning for both admission and discharge to ensure all information is passed on effectively and avoids things being missed.

5.60. Flagging Alert System

Continue to add to the Patient Administration system a flag to highlight when a patient has ASD. This automatically sends an email to the Acute Liaison Nurse team to alert them that patient.

5.61. Complaints

Service users and/or carers should be supported to use the hospital's complaints procedure if there are concerns that cannot be addressed by ward or clinic staff. The Patient Advice and Liaison Service (PALS) can assist with addressing concerns and issues on behalf of service users and carers. An easy to read leaflet has been produced providing information on how to comment or complain.

6. Dissemination and Implementation

6.1. This Protocol is to be implemented and disseminated through the organisation immediately following ratification and will be published on the organisations intranet site document library. Access to this document is open to all.

6.2. The Protocol will be launched via the RCHT daily communication network.

6.3. The Protocol will be available to all external stakeholders via the Documents Library on the Intranet.

6.4. This Protocol document will be held in the public section of the Documents Library with unrestricted access, replacing the previous version which will be archived in accordance with the Trust Information Lifecycle and Corporate Records Management Policy.

6.5. This Protocol will be shared with the Community Cornwall Autism partnership Group and leadership groups for people with ASD.

6.6. Provision of mandatory safeguarding adults training, including the Mental Capacity Act, will be delivered by the Learning and Development Department as outlined in the RCHT Core Training Policy. Reference to relevant sections from this Policy will be utilised at all RCHT Level 1 & 2 Safeguarding Adults mandatory training.

7. Monitoring compliance and effectiveness

Element to be monitored	Standards of Practice by undertaking an audit.
Lead	The Acute Liaison manager will lead on this
Tool	An Audit will be used – by selecting patient notes and making contact to ask if the standards of practice were followed
Frequency	
Reporting arrangements	The completed audit report will be discussed at the Safeguarding Adults Operational Group (SAOG)
Acting on recommendations and Lead(s)	Where the report indicates sub optimal performance the Chair of SAOG will nominate a group member to produce an action plan. The SAOG will be responsible for monitoring progress and will undertake subsequent recommendations and further action planning for all deficiencies identified within agreed timeframes.
Change in practice and lessons to be shared	Required changes to practice identified will be documented in the action plan outcomes. The membership of the SAOG will identify a lead to take each change forward across divisions as appropriate. Lessons will be shared with all relevant parties.

8. Updating and Review

8.1. This process is managed via the document library; review will be undertaken in September 2016 unless best practice dictates otherwise.

9. Equality and Diversity

9.1. This document complies with the Royal Cornwall Hospitals NHS Trust service Equality and Diversity statement which can be found in the ['Equality, Diversity & Human Rights Policy'](#) or the [Equality and Diversity website](#).

9.2. Equality Impact Assessment

The Initial Equality Impact Assessment Screening Form is at Appendix 2.

Appendix 1. Governance Information

Document Title	Protocol for Care of Children and Adult Patients With Autism Spectrum Disorder			
Date Issued/Approved:	6 Jun 14			
Date Valid From:	6 Jun 14			
Date Valid To:	6 Jun 17			
Directorate / Department responsible (author/owner):	Daniella Rubio-Mayer Acute Liaison nurse Manager for Children and Adults with Learning Disabilities and or with Autism Spectrum Conditions.			
Contact details:	01872 252875			
Brief summary of contents	To enable staff at the acute Trust to develop a better understanding of people with ASD and to equip them to deal more effectively with the particular needs of each individual. To clarify for residential and other ASD staff attending the hospital with a person with ASD their supporting/caring role and the boundaries between their caring role and the nursing role of the professional hospital staff.			
Suggested Keywords:	Autism, Safeguarding, Asperger's syndrome			
Target Audience	RCHT	PCH	CFT	KCCG
	✓			
Executive Director responsible for Policy:	Executive Director of Nursing Midwifery & Allied Health Professions			
Date revised:	New document			
This document replaces (exact title of previous version):	New document			
Approval route (names of committees)/consultation:	Safeguarding Adults Operational Group Nursing, Midwifery & AHP's Professional Forum			
Divisional Manager confirming approval processes	Director of Nursing			
Name and Post Title of additional signatories	Not required			
Signature of Executive Director giving approval	{Original Copy Signed}			
Publication Location (refer to Policy on Policies – Approvals and Ratification):	Internet & Intranet	✓	Intranet Only	
Document Library Folder/Sub	Clinical / Safeguarding Adults			

Folder	
Links to key external standards	None
Related Documents:	Equality and Diversity Strategy.
Training Need Identified?	Yes-RCHT is responsible for ensuring all clinical staff are offered training with regards to the key aspects of supporting children and adults with autism spectrum disorders.

Version Control Table

Date	Version No	Summary of Changes	Changes Made by (Name and Job Title)
May 2014	V1.0	Previous version history not known	Daniella Rubio-Mayer Acute Liaison Nurse Manager

All or part of this document can be released under the Freedom of Information Act 2000

This document is to be retained for 10 years from the date of expiry.

This document is only valid on the day of printing

Controlled Document

This document has been created following the Royal Cornwall Hospitals NHS Trust Policy on Document Production. It should not be altered in any way without the express permission of the author or their Line Manager.

Appendix 2. Initial Equality Impact Assessment Form

Protocol for Care of Children and Adult Patients With autism spectrum disorders	
Directorate and service area: : All Clinical Divisions and service areas	Is this a new or existing Policy? New Protocol
Name of individual completing assessment: Daniella Rubio-Mayer	Telephone: 01872252875
1. Policy Aim* Who is the strategy / policy / proposal / service function aimed at?	This protocol's aim is to ensure that all patients with autism spectrum disorder receive equitable health care. It applies to all RCHT staff involved in the care, treatment and support of people with autism spectrum disorders.
2. Policy Objectives*	To ensure the appropriate training is in place that informs health professionals about the local procedural arrangements for working with patients who have autism spectrum disorders.
3. Policy – intended Outcomes*	To empower people with autism spectrum disorders and ensure they receive equitable care. To ensure that the Equality Act and associated legislation are embedded into clinical practice.
4. *How will you measure the outcome?	Documentation audit, patient experience feedback.
5. Who is intended to benefit from the policy?	All patients who have a learning disability. All RCHT staff involved in the care, treatment and support of people with autism spectrum disorders.
6a) Is consultation required with the workforce, equality groups, local interest groups etc. around this policy?	Yes consultation with the Cornwall Autism Partnership group is required.
b) If yes, have these *groups been consulted?	Yes
C). Please list any groups who have been consulted about this procedure.	N/A

7. The Impact			
Please complete the following table.			
Are there concerns that the policy could have differential impact on:			
Equality Strands:	Yes	No	Rationale for Assessment / Existing Evidence
Age		✓	This Protocol strengthens and clarifies the Trust's expectations that the Autism Act, the Autism Strategy and Equality Act are adhered to and are correctly implemented. It aims to ensure that patients with autism spectrum disorders are empowered and receive equitable health care.

Sex (male, female, trans-gender / gender reassignment)		✓	
Race / Ethnic communities /groups		✓	
Disability - Learning disability, physical disability, sensory impairment and mental health problems		✓	
Religion / other beliefs		✓	
Marriage and civil partnership		✓	
Pregnancy and maternity		✓	
Sexual Orientation, Bisexual, Gay, heterosexual, Lesbian		✓	
<p>You will need to continue to a full Equality Impact Assessment if the following have been highlighted:</p> <ul style="list-style-type: none"> • You have ticked “Yes” in any column above and • No consultation or evidence of there being consultation- this <u>excludes</u> any <i>policies</i> which have been identified as not requiring consultation. or • Major service redesign or development 			
8. Please indicate if a full equality analysis is recommended.		Yes	No ✓
9. If you are not recommending a Full Impact assessment please explain why.			
Signature of policy developer / lead manager / director		Date of completion and submission	
Names and signatures of members carrying out the Screening Assessment		1. 2.	

Keep one copy and send a copy to the Human Rights, Equality and Inclusion Lead,
c/o Royal Cornwall Hospitals NHS Trust, Human Resources Department, Knowledge Spa,
Truro, Cornwall, TR1 3HD

A summary of the results will be published on the Trust’s web site.

Signed _____

Date _____