

**YOUNGER PEOPLE WITH DEMENTIA TEAM
OPERATIONAL PROCEDURE & STANDARDS**

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Why we need this Procedure

The Younger People with Dementia Team (YPD) is a specialist county-wide service which provides assessments and interventions for adults under 65 years of age who are suspected of having dementia.

The team also provides care-coordination for younger people with dementia who have complex needs and require ongoing specialist support.

It is estimated that there are currently over 42,325 younger people with dementia in the UK, (dementia UK 2nd ed (2014), Alzheimer's society). This represents approximately 5% of the 850,000 people with dementia. It is widely accepted however that dementia in younger people may be higher than this figure due to differences in the way that data on older and younger people is collected.

In Northamptonshire due to a larger working age population than the UK average, it is estimated that the number of people with dementia is between 200 and 550, or between 2.4% and 7.2% of all people with dementia in the county (2012.)

Key drivers for specialist YPD teams nationally include:

Diagnostic challenges associated with early-onset dementias:

- younger people tend to have rarer types of dementia
- early onset dementias are more easily mistaken for other types of mental illness
- the average wait nationally for younger people from the first symptoms to diagnosis is four years

The needs of younger people are often very different to older people and therapeutic interventions need to be tailored accordingly:

- Younger people are more likely to be in paid employment and may require advocacy to allow them to continue work
- They are more likely to have dependent children
- They are more likely to experience financial problems
- They are more likely to have a hereditary form of dementia with implications for their family

A national shortage of supportive services:

- many day care facilities and care homes are not registered to accept younger people with dementia
- younger people often prefer different, more active activities to older people with dementia
- younger people often present challenges in that they tend to be physically fitter and stronger posing greater risks to staff where aggression is present and leading to greater staff anxiety

What the Procedure is trying to do

The aim of this procedure is to set out the standards and expectations for the Younger People with Dementia Team (YPD) within Northamptonshire Healthcare Foundation NHS Trust.

Key duties

Principles Underpinning Service Delivery

- A specialist countywide team with the skill and expertise to provide a timely, accurate and sensitive diagnosis
- Access to a full range of diagnostic and supportive services
- A nurse-led holistic, patient-centred and 'Recovery' orientated model of care
- A team which promotes inclusion and assists service users and their families in reducing the effects of stigma
- A team which is flexible in service delivery, taking into account that many people and/or their partners often work during office hours
- A community-focused team which sees people at home wherever possible
- A team which is sensitive to social inequalities with regards to gender, age, ethnicity, class, disability and sexual orientation
- Practice is evidenced-based and in line with requirements of Clinical Governance, and Department of Health Guidelines
- Resources are used as efficiently and effectively as possible

Aims of the YPD Team

- To provide specialist assessment, care planning, treatment, care, support, monitoring and review of younger individuals with dementia
- To minimise experiences of impairment and disability and to empower them to lead a fulfilling and meaningful life, or to 'live well with dementia'
- To provide a timely, accurate and sensitive diagnosis
- To ensure that the YPD team is interlinked with all services and that pathways are clear
- To support family carers in their caring roles and help them maintain their health and wellbeing

- To give advice, information and support to primary care services and other local agencies in the management of younger people with dementia and work in partnership with them in the effective provision and delivery of care

Objectives of the YPD Team

- To continually strive towards providing the best possible, most up to date care through staff education and development
- To facilitate access to a full range of health and social care services for promoting mental and physical wellbeing and self-determination.
- To provide a clear and seamless care pathway facilitated by closer working relationships with service users, carers, other secondary services, primary care and voluntary and non-statutory agencies.
- To provide a proactive, collaborative and educative approach to treatment and follow-up.
- To ensure the continuous audit, monitoring and improvement of practice and service delivery.

Multi-Disciplinary Team Approach to Care

The YPD team, while nurse-led, has close links with other professional groups working within the Memory Assessment Service (medical and psychology). This also includes mental health locality teams, social work, GP services, acute liaison, Kettering General, Hospital, Northampton General Hospital, Care homes and Neurology. Further on occasions we work closely across different counties to ensure a smooth transition of care. The Team values the contribution of each profession, working together in an integrated approach to care.

Procedure detail

Eligibility Criteria

The YPD Team provides a service to adults between the ages of 18 and 65 who are either:

- Presenting with symptoms of dementia and require a formal assessment as part of the Trust Memory Assessment Service
- People who already have a formal dementia diagnosis and are under the age of 65 but who currently require further assistance and support. This includes people who:
 - ❖ are taking cognitive enhancing drugs which require regular review by secondary mental health services
 - ❖ people with more complex needs and/or challenging behaviour
 - ❖ where there is significant risk of harm to the person and/or to others or where the level of support required exceeds that which can be offered by primary care
 - ❖ where there are complex problems of management and engagement

- ❖ where there is significant problem with carer stress
- ❖ potentially fall between gaps in services

Services Provided by the YPD Team

The team has access to all of the services provided by the Memory Assessment Service including Cognitive Stimulation Therapy, psychological services and occupational therapy in line with NICE (2011) guidelines and the National Dementia Strategy (DoH, 2009.)

In addition the YPD team provides:

- Specialist, comprehensive and holistic assessment of mental health and social care needs
- Risk assessment and management plan which is negotiated with the person and their family
- Diagnosis of dementia (where applicable) including its subtype
- Written information together with verbal advice about the person's illness, including symptoms and likely future needs
- Advice as to the person's suitability for cognitive enhancer medication, and facilitating a trial of this medication if it is clinically indicated and is the person's wish
- Care co-ordination - care planning with service users and carers; support and relapse prevention; monitoring; regular review and liaison with individuals and services involved.
- Provide follow-up to service users discharged or on leave from hospital in line with the Protocol for 7-Day / 48-Hour Inpatient Discharge Follow up.
- Psychological interventions – according to the assessed need of the service user.
- Medication management – in liaison with primary care, CMHT's will prescribe, administer, monitor medication and its side effects, and encourage concordance with prescribed medication.
- Assessment and support with Activities of Daily Living.
- Liaison with Approved Mental Health Professional (AMHP) service for Mental Health Act Assessments.
- Health promotion and bio psychosocial education.
- Assistance to service users to develop Advanced Statements.
- Support in accessing educational, employment and other opportunities.

- Carers assessment, support and education.
- A specialist YPD liaison service to general hospitals, acute adult mental health wards, and mental health wards for older people

Care Programme Approach (CPA)

The CPA provides the framework for the delivery of mental health services and seeks to ensure that service users meeting these criteria receive:

- An assessment of their health and social care needs.
- An up-to-date care plan.
- Regular review of their care.
- A named CPA care co-ordinator
- An up-to-date risk screening/assessment in line with the Trust Risk Management Strategy (CRM001.)

Service users and where appropriate, their carers are integral in the planning, delivery and evaluation of their care.

Service users and their carers will be encouraged to take an active part in the processes described in full in the CPA Policy and Practice Guidance (CLP010).

Working with Other Trust Services

The YPD Team is interlinked with other Trust services as set out in the paragraphs below. The Team Manager has responsibility for ensuring that pathways are clear and that patients when needing other specialist services are referred quickly and efficiently.

The team will work closely with Urgent Care & Treatment (UCAT) to ensure that service users referred under the very urgent care pathway are screened and assessed. In addition, the team will refer to UCAT staff for service users who are experiencing acute mental health problems and who may benefit from home treatment as an alternative to in-patient admission.

The team will follow up service users in in-patient units, liaising with in-patient staff and participating in planning their discharge back to the community.

The team will liaise with and as necessary refer to other specialist teams e.g. Brain Injury team, Learning Disability Teams, psychology services, MS nurses, Parkinson's Disease nurses, mentally disordered offenders services, and Rehabilitation services.

The team will refer to the relevant policies for guidance when operating at the interface between services:

- MHSOP Inpatient Operational Policy
- Adult Mental Health Acute Inpatients Admissions (OP – AMHAIA)
- Standing Operation Procedure for Transition for Older and Younger Adults within Mental Health Services

Working with Primary Care Services

The YPD Team will continue to work with primary care services in developing a robust partnership, good communication and close collaborative working. The person's GP should

be regularly updated about any changes in the person's care, including when cognitive enhancer medication is being started.

Secondary Care Liaison

The team will work collaboratively with other secondary services including mental health and learning disability services, carrying out joint assessments as necessary if there is uncertainty about which team should provide the initial assessment.

Working with Voluntary and Non-statutory Agencies

The YPD Team will promote effective liaison and collaborative working partnerships with local voluntary and non-statutory agencies that will be of benefit to service users. This is likely to include organisations such as; the Alzheimer's Society, MIND, Headway, Northamptonshire Carers, Welfare Rights, and the Centre for Independent Living (CIL) amongst others.

Management and Structure

The YPD team is led by a Team Manager who carries a clinical caseload.

The Team Manager has responsibility for the day-to-day operational management and functioning of the Team, including deployment of resources, meeting clinical governance targets and adhering to Trust policies and procedures. The manager provides scheduled clinical supervision for staff within the team.

The Team Manager has overall responsibility for the clinical work of the team, for ensuring that the team is working to best practice, and that clinical pathways are clear and understood by all. They are available to all staff as and when needed to support and guidance with clinical issues and ensure the continued development of the service and forward planning in the Team.

The YPD Tem has a clinical meeting weekly to facilitate the allocation of referrals, discussion of assessment outcomes, review of on-going cases and those for discharge, amongst others.

Meetings will also facilitate input from all members of the Team and will ensure that concerns and differences of professional opinion are fully discussed and a course of action agreed.

Performance Management

The team will comply with the Trust's performance management, data quality and data entry requirements.

Where there is non-attendance and where there is loss of contact with the service user, the Trust's DNA Policy will be followed respectively.

Performance data will be used by the team manager to manage, monitor, improve and develop Team performance and to provide the necessary information for reporting requirements.

Waiting times will be managed effectively and consistently so that service users do not wait longer than agreed standards on screening assessment and treatment.

The Trust Electronic Patient Record (EPR) System One is available 24/7. The minimum data set and relevant clinical information about the service user will be entered in the EPR and accessed as necessary.

All staff using the EPR will be responsible for entering, maintaining and ensuring their data quality.

Confidentiality

Information relating to service users and carers will be safeguarded and maintained by all staff in line with the Trust Information Governance Policy (IGPr002)). However where sharing or disclosure of information is necessary, the team will refer to the Trust's Policies for information governance which are available on the Trust internet and which include the following:

- Health Records Management Policy (IGP107)
- Use of Info and Technology Policy (IGIS01)

Service User and Carer Involvement

The YPD team promotes and encourages service user and carer involvement as it results to better outcomes of individual care, provision of more locally responsive services and greater ownership of health services.

The YPD Team will involve service users and carers in the following wherever possible in line with the Trust:

- Decisions about their own treatment and care.
- Giving feedback about the quality or type of health and social care received.
- Planning and development of future services
- The interviewing of staff as part of the YPD team recruitment process
- The training of staff about dementia

Service users and their carers who have concerns about their care can resolve issues through their care coordinator in the first instance. If concerns about care or service delivery remain, service users will have access to the Patient and Advisory Liaison Service and the Complaints Procedure.

Recommendations arrived at from service user and carer feedback will guide the team to improve and develop its services.

Access to Clinical Records

Service users who wish to access their clinical records can do so in line with the Trust Policy on Access to Health Records (IGP112).

Clinical Effectiveness and Audit

Quality of service delivery will be improved by ensuring that service users are actively involved in their care, that interventions are research and evidence-based and appropriate to the needs of the individual.

Clinical outcomes and local implementation will be measurable and monitored/audited in line with National Service Frameworks and NICE guidelines. Regular local and Trust-wide audits will monitor these.

Service users, carers and other stakeholders will be encouraged to participate and contribute to the development of the clinical audit programme, among others.

Service managers and Clinical Team Leaders will take the lead in initiating and / or sharing information generated from audits.

Serious Incident (SIs)

Where available, learning and recommendations from critical incidents or reports from National Confidential Inquiries will be discussed during weekly team meetings and incorporated into practice in order to improve care and service delivery.

Training and Continuing Professional Development

All staff members attend mandatory training as required, and are responsible for ensuring that they attend any training that they are booked onto.

All staff receive an annual appraisal which includes a personal development plan.

All clinicians in the team receive clinical (professional) supervision, and the team manager and nurse consultant also receive managerial supervision in line with Trust Policy.

Where appropriate, multi-professional and multi-agency training will be developed and provided to improve collaborative work and to enable more effective service delivery to service users and carers.

The team has organised peer group meetings on a two monthly basis which includes educational slots and the developmental needs of the team.

The training of students and trainees to the highest standards is critical and the team hosts placements for student nurses.

Team Safety

In line with the Trust Lone Working Policy the team will ensure that local strategies are in place to ensure safe working.

Management of Non-Clinical Risks

Every member of the team is able to access policies, procedures and guidelines on managing non-clinical risks on the Trust website. New members of staff are directed towards these during their Trust and local induction. These include among others:

- Health and Safety Policy (HSC001)
- Fire Policy (HSC003)
- Workplace Policy (HSC005)
- Moving and Handling Policy (HSC010)
- Working with Display Screen Equipment Policy (HSC014)
- Environmental Policy (HSC015)
- Policy on the Control of Substances Hazardous to Health (HSC016)

- Visitors Access to Sites Policy (HSC024)
- Violence and aggression Policy (HSC029)

All staff are responsible for ensuring that they keep up to date with policies, and attend mandatory training. They are also responsible for alerting the team manager of any workplace risks or hazards that they identify. The team manager is responsible for managing these risks in line with the Risk Management Strategy (CM001) which includes entering risks which cannot be managed within the team onto the Team Risk Register.

Management of Employment and Human Resource (HR) Matters

Team members can find the most up to date Trust policies, procedures and guidelines on managing employment and HR matters on the Trust internet. Key documents for staff to refer to include:

- Disciplinary Policy and Procedure (HR001)
- Grievance Procedure (HR002)
- Organisational Change (HR003)
- Managing Diversity and Equal Opportunities in Employment (HR007)
- Staff raising Issues of Concern (HR009)
- Time Owing Procedure (HR006)

Training requirements associated with this Procedure:

Mandatory training is not a requirement of this procedure.

How this Procedure will be monitored for compliance and effectiveness

The YPD Team Operational Procedure is a working guide for all team members. It also serves to inform primary care services, local statutory and voluntary services, service users and carers about the YPD Team.

This Operational Procedure and Standards will be reviewed three yearly to reflect major changes in national policy and practice and feedback from local stakeholders and service user experience.

Dissemination & Implementation

The new version of the procedure will be available on the Trust Intranet and brought to all staff's attention through the staff room.

In addition the team manager will bring the procedure and any revised additions to the attention of all staff in the YPD Team.

For further information

References

NICE (2011) guidelines National Dementia Strategy (DoH, 2009.)
Dementia UK 2014-Alzheimers Society.

Equality considerations

Equality Statement

The Trust aims to design and implement policy documents that meet the diverse needs of our services, population and workforce, ensuring that none are placed at a disadvantage over others. It takes into account current UK legislative requirements, including the Equality Act 2010 and the Human Rights Act 1998, and promotes equal opportunities for all. This document has been designed to ensure that no-one receives less favourable treatment due to their reassignment, sexual orientation, marriage and civil partnership, race, religion or belief, pregnancy and maternity. Appropriate consideration has also been given to gender identity, socio-economic status, immigration status and the principles of the Human Rights Act.

In carrying out its functions, the Trust must have due regard to the Public Sector Equality Duty (PSED). This applies to all the activities for which the Trust is responsible, including policy development, review and implementation.

Due Regard

This procedure has been reviewed in relation to having due regard to the Public Sector Equality Duty (PSED) of the Equality Act 2010 to eliminate discrimination, harassment, victimisation; to advance equality of opportunity; and foster good relations. Due regard comprise two linked elements: proportionality and relevance. The weight given to equality should therefore be proportionate to its relevance to a particular function. It should also be noted that there will policies/proposals that have no impact and little relevance to equality. This procedure is specific to a target group defined in the eligibility criteria namely those people who present or have symptoms of dementia and require a formal assessment or diagnosis and are between 18-65. The potential of any negative impact on those outside of the age criteria is limited as services are provided for those patients through other pathways such as Memory Assessment Services (MAS) or Community Mental Health Services (CMHT) for Older People (over the age of 65). Other considerations will be given in relation to support for BME young people or woman and this target group could be support through reverse commissioning. The target group for individuals who do not have English as their first language will be supported through interpreter services. The YPD team additionally promotes and encourages service user and carer involvement as it results to better outcomes of individual care. This procedure also states that the Trust will promote effective liaison and collaborative working partnerships with local voluntary and non-statutory agencies that will be of benefit to service users. The team will liaise with and as necessary refer to other specialist teams e.g. Brain Injury team, Learning Disability Teams, psychology services, MS nurses, Parkinson's Disease nurses, mentally disordered offenders services, and Rehabilitation services.

The Trust works in accordance with its Equality, Inclusion and Human rights policy and its Equality, Inclusion and Human rights strategy.

Document control details

Author:	Jenny Kerti
Approved by and date:	27/02/2017
Responsible committee:	Clinical Executive
Any other linked Policies:	<p>Health and Safety Policy (HSC001) Fire Policy (HSC003) Workplace Policy (HSC005) Moving and Handling Policy (HSC010) Working with Display Screen Equipment Policy (HSC014) Environmental Policy (HSC015) Policy on the Control of Substances Hazardous to Health (HSC016) Visitors Access to Sites Policy (HSC024) Violence and aggression Policy (HSC029) Disciplinary Policy and Procedure (HR001) Grievance Procedure (HR002) Organisational Change (HR003) Managing Diversity and Equal Opportunities in Employment (HR007) Staff raising Issues of Concern (HR009) Time Owing Procedure (HR006)</p>
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Version No.	Date Ratified/ Amended	Date of Implementation	Next Review Date	Reason for Change (eg. full rewrite, amendment to reflect new legislation, updated flowchart, minor amendments, etc.)
1	27/02/2017	28/02/2017	27/02/2020	No Operational Procedure in place