Livewell Southwest

Plymouth Community Memory Assessment, Treatment and Diagnostic Service and including the Huntington Disease Service as a supplement

Version no.2

Review: May 2019

Notice to staff using a paper copy of this guidance

The policies and procedures page of LSW intranet holds the most recent version of this document and staff must ensure that they are using the most recent guidance.

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Reader Information

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	Protocol
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Document review history

Version no.	Type of change	Date	Originator of change	Description of change
0.1	New document	January 2011	Consultant Clinical Psychologist/ Manager	
1	Ratified	February 2011	Policy Ratification Group	Minor amends.
1.1	Extended	March 2013	Sara Mitchell	Extended, no other changes.
1.2	Extended	January 2014	Deputy Locality Manager	Extended, no other changes.
1.3	Extended	August 2014	Deputy Locality Manager	Extended, no other changes.
2	Reviewed	April 2016	Deputy Locality Manager	Reviewed minor amendments

Plymouth Community Memory Assessment, Treatment and Diagnostic Service and including the Huntington Disease Service as a supplement.

1 Introduction

The document outlines the operational policy of the Community Memory Assessment, Diagnostic and Treatment Service (CMS) and reflects the changes following the reconfiguration of OPMH services in Autumn 2009. This includes services for those people with an early onset dementia Service and the Huntington Disease Service. The Huntington Disease Service is managed with the CMS and the shared similarities of the service are reflected within the CMS operational policy. Where there is divergence of form and function these are represented in the Plymouth Huntington Disease Operational Policy which is attached as Supplement 1.
Both services are city wide and aim to identify and provide a service to all relevant individuals within the city.

The philosophy underpinning the Community Memory Service (CMS) in Plymouth is based on the following:

- A service user centred approach to meeting individual needs
- National Dementia Strategy (February 2009)
- Local Dementia Strategy (2010-2013).
- Local Dementia Strategy (2013-2016)
- A learning organisation – based on reflective practice and monitoring, evaluating progress as well as measured, positive risk taking
- The Care Programme Approach (CPA) or Single Assessment Process (SAP)
- Everybody's Business Guidance Principles
- New Ways of Working Guidance Principles
- New Horizons: A Shared Vision for Mental Health
- Transforming Community Services
- Fair Access to Care
- Putting People First
- Local Carer Strategy
- The Mental Capacity Act 2005
- Promoting dignity, respect and diversity agenda

The operational ethos of the Community Memory Service is one which operates under the '3 R's' :

Responsibility- working together to provide a robust auditable service that meets needs appropriately and efficiently
Reciprocity- working together and acknowledging the importance of relevant partner agencies in delivering an optimum standard of care
Relationships- no sector or person in the service is more important than another, the service is provided from a team base which trusts each other

This Policy should be read in conjunction with all of the above. It is the responsibility of Professionals from all disciplines to ensure familiarity with the Mental Health Act Mental Capacity Act and associated Codes of Practice and with current Livewell Southwest Clinical Policies.

2 Purpose

The policy describes the current function and operation of the Plymouth Community Memory Service which has been developed with the help and agreement of colleagues to meet the local and national strategies for people with a dementia. Its purpose is to give clarity about its role and function to key stakeholders

The service is ageless and is provided for:

- Adults referred to the service from within Plymouth City boundaries or GP practices covered by the Plymouth NHS presenting with primary concerns about their memory
- Individuals referred to the service by other health/social care professionals where clarification of memory function would be helpful in planning optimum care and management

It is intended to achieve:

- Assessment, diagnosis, treatment and ongoing review during the early stage of their illness, to maintain optimum personal and social functioning
- Support personal and professional carers to reduce carer burden
- Support the delivery of improved public and professional awareness of dementia through education and support

3 Duties

The duties of the service are :

- To provide services which are safe and effective and are delivered in the least restrictive and disruptive manner possible, ideally through co-location of community staff working within the service and by the use of a single

set of multi disciplinary and integrated notes.

- Have a single point of access into the service
- Provide ongoing holistic and robust assessment of memory and its impact on social ADL and community living
- Reduce the stigma associated with a diagnosis or possible diagnosis of dementia through appropriate training and education
- Optimise social functioning and promote independence
- Work alongside colleagues in all areas of health and social care provision to deliver a truly seamless service
- Through collaboration, increase the capacity of local resources to meet the needs of people presenting with memory difficulties
- Provide prompt and expert diagnosis, assessment and treatment of memory difficulties
- Provide effective, evidence based treatments
- Provide advice and support to service users, families and carers
- Assist service users and carers in accessing support
- Establish a detailed understanding of all local resources relevant to support of individuals and promote effective partnership working for people in the early stage of dementia.
- Provide support and advice to the wider health, social care and third sector community in relation to education, clinical governance and the promotion of service user involvement
- Collect relevant data as requested by Livewell Southwest and commissioning team and to assist in the maintenance and updating of GP practice based registers for people with a dementia.
- Gain a detailed understanding of the local population, its demographic demand needs and priorities, and provide a service that is sensitive to this and issues relating to diversity
- Provide a culturally competent service, including ready access to interpreter services for minority languages and British Sign language
- Minimise the use of emergency respite and hospital admissions
- To participate and contribute to relevant research

The Community Memory Service aims to promote and develop partnerships and inter-agency working between health, social services, voluntary sector agencies and housing. This will be through robust liaison and practice, teaching, education and training of which all members of the service may be asked to participate.

The policy has been devised with the help and advice of colleagues within the service.

The Chief Executive and relevant directors are ultimately responsible for the content of all policies and their implementation and the Locality Managers will support and enable Managers to fulfil their responsibilities and ensure the effective implementation of this policy.

Clinical staff have a responsibility for ensuring this policy is carried out.

4 Definitions.

CMS - Community Diagnostic, Assessment and Treatment service
CCDT – Complex Care Dementia Teams
BPSD – Behavioural and Psychological Symptoms of Dementia
ACI – Acetylcholinesterase inhibitor i.e. cognitive enhancer medication
NP- Nurse Prescriber
MSN- Memory Service Nurse
CSW- Community Support Workers
QMSS- Qualified Memory Service Staff

5. How the service works

The CMS views dementia as a journey with 'stages' (see appendix 1). The aim of the CMS is to support the person and their carers, through stages 1 and 2 (Clusters 18 and 19) of that journey.

The CMS is an important and fundamental part of Livewell Southwest's comprehensive Integrated Mental Health Service. The Community Dementia Pathway which the CMS is part of links closely with social care and the Alzheimer's society to provide an integrated pathway of care.

5.1 **Staffing**

The CMS is currently managed within Older People's Mental Health Services and consists of :

- Community Psychiatric Nurses with specialist knowledge/experience in Dementia Care (Memory Nurses),
- Psychiatrists,
- Nurse Prescriber (NP)
- Occupational Therapists,
- Clinical Psychologists,
- Community Support Workers (CSW),
- Community Care workers (CCW),
- Carer Support Worker (CCW carer),
- Secretarial and Administration Staff.
- Adult Social Care colleagues

Students of various disciplines will often become temporary team members during learning placements within the Older People's Mental Health Services.

5.2. **Service Delivery**

The service will be delivered by

- Home visits
- Clinic Appointments
- Relevant Investigations and referrals
- Reviews

The service will support

- Involvement in the Access to Mental Health Duty Service
- Twice weekly Support and Advice Line for the Health and Social Care Community.

It will uphold the standards and processes set in Care Programme Approach (CPA)/SAP and in relevant legislation

5.3 **Referrals**

Referrals will be accepted through

- DRSS
- Access to Mental Health
- Social Care
- Self referrals (on the understanding that the GP will be made aware)

'Emergency' referrals will only be accepted from GPs and will be responded to by discussion with consultant and member of the CMS team
'Routine' referrals will be seen within 28 working days.
'Urgent' referrals will be seen in 7 working days.

The aim of the CMS from first contact to consultant clinic appointment (if appropriate) will be 10 weeks. (National Dementia Strategy 2009)

Referrals from non-GPs will usually be by letter/CPA/SAP format.
'Emergency' or 'urgent' referrals information can be sent by 'fax' (following the PCT faxing policy to safeguard confidential information)

GP referrals will be triaged via DRSS who have the relevant referral criteria as agreed with Medical staff.

The CMS is a service targeted for those people presenting with memory difficulties of no known cause. Those people with neurological illness e.g.

MS, CVE, difficulties relating to substance abuse, or under Adult Mental Health care or OPMH Liaison can access the service if there is a case that assessment will provide a significant help in the care and management of the individual but they may NOT necessarily remain within the CMS. They will be signposted to the most appropriate service. The number of those referrals will be closely monitored.

The CMS will exclude those people under LD services who currently have their own bespoke monitoring and treatment programme

Older people who present at initial, or subsequent assessments as vulnerable will be referred to the appropriate Vulnerable Adult Coordinator for specialist advice and follow up if required.

Individuals who require the input of Social will be referred and their needs assessed under Fair Access to Care Services (FACS)

5.4 Hours of operation

CMS offices will be open to receive calls during the following hours:
0800 – 1700 Monday to Friday
At other times, a message will be heard advising callers to contact out of hours (where their call is urgent or an emergency)

5.5 Operational availability

All practitioners will ensure that they are contactable during the routine working day. Mobile phones will be made available.

Contact numbers must be maintained within the office base and distributed to all CMS colleagues

Important for operational efficiency and safety is the staff team clip board and this will be maintained within the office and available for colleagues and managers.

5.6 Assessment

The CMS/CPA initial, holistic assessments will be undertaken at first contact

Following this assessment onward referrals will be made and a preliminary plan agreed with the patient and carer (if appropriate). This may include

referral for :

- Consultant Clinic for diagnosis and/or further assessment/investigation within 18 weeks of initial referral
- Consultant Physician clinics for clarification of physical health status
- Memory strategy groups (Memory Club)
- Carers education and training group
- Watchful Waiting (serial assessment in 6 + months)
- Discharge back to GP or referrer
- Referral/signposting to other agencies
- An OT Home safety assessment will be offered to all those referred who live alone
- Further input by CMS Clinical psychology
- 'Clinic at Home' is available in exceptional circumstances following discussion with relevant Consultant
- Consultant and Clinical Psychology 'Early onset/Atypical ' Clinic

At the assessment a letter outlining the agreed plan of care will be left with the individual and a comprehensive letter will be sent to the GP and/or referrer advising of plan as agreed with patient and copied to the patient/carer as per Trust policy.

5.7. **Clinics.**

Clinics are held in LCC Out Patients Mount Gould Hospital.
There are regular Consultant Clinic sessions per week, Nurse Led Review and Prescribing Clinics and Nurse ACI Monitoring Clinic.
consultant Clinic is a medical student teaching clinic.
In addition there is a 'Early Onset and Atypical Clinic' and a monthly Clinic with a Consultant Physician.

5.8 **Treatment**

Treatment is deemed to start once an assessment has been made by a Memory Nurse or the Consultant has agreed to further assess in the CMS.

If ACIs have been prescribed by the Consultant at clinic the person will be followed up in line with NICE Guidelines
A Statement of care will be written and agreed with the patient outlining the process to be followed. This will be in one of three ways, according to individual need.
Level 1. Medication will be started and reviewed by a Memory Service Nurse in a nurse led clinic
Level 2. Medication will be started and reviewed by a Memory Service

Nurse at titration points by a home visit.
Level 3. Medication will be started and reviewed by a Memory Service Nurse and reviewed more frequently by the Memory Service and Community Support Worker by home visits.

Any concerns or adverse side-effects will be discussed with the Consultant. The GP will be advised of any resulting change to medication and the Statement of Care changed to reflect this.

After 3 months prescribing will transfer to the GP under the shared care agreement.

Continuation of the medication will be reviewed at 6 months. If the patient is not maintained at their pre-medication level or no improvement or change has been noted the medication will be discontinued and the GP informed. However they will remain under review while they are clustered at 18 or 19 and show no behavioural disturbances (BPSD).

If ACI medications has not been prescribed the Consultant will either discharge or review in clinic and will remain lead practitioner unless they are referred to a nurse led clinic.

A summary of the clinic discussion will be offered to the patient/ carer and the GP will be advised of the clinic outcome via a copy of the clinic outcomes form and a Consultant letter.

The Consultant will make a clinical decision about when and with whom reviews can then take place. This will be reported to the clinic nurse and recorded on the outcome sheet.

All instances of disengagement and failure to comply with treatment must be raised at the weekly team meetings when a positive action will be agreed and recorded.

5.9 **Reviews**

Reviews might take a variety of forms

- Further assessment for those on Watchful Waiting as agreed at initial assessment (episode open for MSN or Clinical psychology caseload)
- Consultant clinic review
- Nurse Prescriber review*
- Memory Nurse Review*
- CSW or phone review

*As agreed by Consultant. The Nurse will open an episode and take the person onto caseload after 1st appointment and complete Statement of Care. This will be given to the patient at clinic and a typed copy sent to the GP.

Everybody in the service will have a review as agreed with the patient.

All contacts will be recorded on SYSTMONE for audit and monitoring purposes. This will include significant telephone calls.

Clustering will be completed at each review. If there is evidence to support a cluster of 20+ the care and support of the individual will be transferred to the Complex Care team after discussion and internal referral.

5.10 **Discharges.**

Patients will be discharged from the service after discussion with the lead professional and will occur when the CMS has no further helpful resources. The aim will always be to have an agreed discharge with the patient and their carers.

In certain circumstances e.g. when the patient has declined assessment or has repeatedly DNA'd appointments the patient will be discharged and the GP/CRT/DRSS informed.

If a person has entered residential or nursing care, has not been, or is no longer prescribed ACI medication and at review is settled the person will be discharged to the care of the GP.

5.11. **Interface with other agencies**

The CMS aims to provide a service supportive of patients, their carers and of the wider health and social care community. These are likely to include:
Alzheimer's Society
Age Concern
Psychiatric Liaison Service (DGH)
District Nursing Service and Health Visiting
Reablement
LCC
Harbour – Drug & Alcohol Services
Palliative care services
GP Link workers
BEM workers

Complex Care Dementia Team
Livewell Southwest Social Care teams

5.12 **Management Structure and process**

Locality Manager
|
Deputy Locality Manager
|
Community Dementia Pathway Manager
|
Qualified Memory Service Staff
|
CSW and Secretariat

The CMS will be congruent with all relevant Livewell Southwest policies and procedures.

5.13 **Communication**

- The CMS weekly meeting is the core of the service and will be attended by as many of the CMS and complex care team as possible. The aim will be to ensure all clinical business is completed with 1 hr. Key performance indicators are reported. Attendance, referral and discussion with care outcomes are logged.
- Monthly 1 hour 'business meetings' will be held to feedback from Assistant Director (AD) and OPMHS operational meetings and review the working of the service. Notes from these meetings will be available to all staff in the team.
- Quarterly meetings will be held with the team to review external KPI and in house performance targets to ensure that the service quality is maintained and is being delivered to commissioner specification.
- Weekly Clinic Nurse led meetings are held to handover information from Clinics and allocate cases.

The Livewell Southwest Line Management Policy will be used to provide guidance in regard to line management and caseload supervision of those people who are in the CMS. All staff are expected to have a clinical supervisor.

5.14. **Absence**

Under normal circumstances, cover for annual leave, sickness or study will be provided by other team members if available. In extreme situations, where operational viability is threatened, for example by sickness across

the team, then the manager must report this to the OPMH Assistant Director at the earliest opportunity.

During periods of planned absence the team will decide on the most appropriate person to provide cover.

It is the responsibility of each practitioner to make a list available detailing what arrangements have been made for specific interventions in respect of clients who need to be seen during any period of absence. This information will be made available on System One.

During periods of unplanned absence, Manager will be notified as early as possible of the absence in line with Absence monitoring policy. Agreement will be reached on what work is essential, what may be deferred for another day and who is the most appropriate professional to undertake the work.

The Secretariat will notify clients of any cancellations immediately.

The CMS will adhere to the Organisation's Confidentiality Policy and all Data Protection legislation in accordance with the data Protection Act

5.15 **Safety and Management of Risk**

The Deputy Locality Manager will be informed of any serious concerns regarding disengagement or non contact and the action taken or required

Where a home visit fails because the client is not at home or no answer can be obtained the surgery will be contacted. A note left in a sealed envelope for the client will be posted through the letter box and a letter or a phone call with an alternative appointment will be sent.

The CMS takes seriously its responsibility for staff safety. All of us however have a responsibility for safe working practices and to follow Health and Safety Guidelines, Lone working policies and the organisation's Zero Tolerance Policy.

All staff must complete a weekly diary sheet and make appropriate amendments each day. Where a home visit or other task is assessed as being high risk it is the responsibility of the practitioner concerned to inform their Manager of the predicted risk. The 'red file' procedure will be implemented if necessary.

A properly drawn up strategy to reduce this risk must be produced and all parties must be satisfied that every contingency has been considered. In

extreme situations of risk Police advise that they should be involved in the risk assessment before the task is undertaken

All clients will be assessed in the most appropriate setting in line with safe working practice policies.

It should be the normal practice that practitioners return to their base following completion of the last home visit. This practice is beneficial in two respects:

- It gives confirmation to managers that all team members are safe
- It provides opportunities for any necessary de-briefing following client contact
- SystmOne entries can be completed in a timely manner

In the unusual event of a practitioner not being able to return to base they must phone in to confirm that they are safe and have concluded their client contact appointments.

For occasions when planned visits after office closure are taking place then a plan must be made for checking on the individuals safe return, as per lone worker policy.

Staff must be aware of their own Professional Codes of Conduct and alert the CMS manager in the rare circumstances of conflict

5.16 **Unmet need**

Should there be a situation whereby the needs of a patient/carer cannot be met, the Unmet need process should be instigated (see CPA policy).

5.17 **Service User and Carer Involvement**

The CMS positively encourages feedback and participation from users and carers.
We will do this by a range of methods including:

- Regular consultation with service users and their carers in order to accurately evaluate the quality of service provision. This will be done using a range of methods, e.g., questionnaires, forums/meetings and anonymous feedback to independent representatives.
- Encouraging the use of advocacy services, where available and possible.

- All documentation outlining planned care is agreed with the patient except in exceptional circumstances.
- Access to personal notes will be in line with Trust's policies.
- Participate actively in the patient satisfaction audit cycle of the Trust

6. Monitoring Compliance and Effectiveness.

- The CMS will actively contribute to data collection as required by Commissioners, Business Intelligence and Finance.
- Compliance with the SLA will be monitored by the relevant accountant
- The overall functioning of the service will be reviewed quarterly at the team meeting and with the AD.
- Feedback about relevant performance matrices will be available to the Older Peoples Programme Board as requested by commissioners.
- The service will comply with regular Trust audits e.g. patient satisfaction, health records peer review.
- SystmOne contacts will be printed and signed on a monthly basis and at the closing of an episode if contacts have not already been recorded in the case notes

Closing Statement

This operational Policy is not exhaustive and will be an evolving and dynamic document requiring revision and modification as the CMS develops.

Supplement 1.

Plymouth Huntington Disease Service Operational Policy

1. Introduction

Plymouth HD service is a city wide service for people in the Plymouth catchment area who are affected by HD. The service offers a wide range of services to people with HD, their families and professionals working with them.

Heathleigh team will always recognise the individual nature of HD and it's impact on people and families.

The service will be available to anyone affected by HD

The team will encourage independence whilst supporting individuals in the complex and often very difficult HD related decisional steps or adjustments that need to be made through the course of the illness and adapting to these transitions and challenges

We recognise that the kind of support needed varies but we aim to provide an accessible and flexible service, working in partnership with the person with HD and where appropriate their family, in collaboration with other statutory and non-statutory services enabling people to cope with their situation

We will continue to develop our expertise and share knowledge and expertise locally, nationally and internationally.

2. Purpose

This Policy provides an outline of the Service Philosophy and Objectives, as well as key services provided.

The purpose is to give clarity regarding the role and function of Plymouth Huntington Disease Service to Staff, Service Users, Carers and other Stakeholders.

3. Duties

This Policy was devised by the staff of Plymouth Huntington Disease Service.

The **Chief Executive** is ultimately responsible for the content of all Policies and

their implementation.

Directors are responsible for identifying, producing and implementing Plymouth NHS Policies relevant to their area.

The **Assistant Director** will support and enable operational Clinical Leads and Managers to fulfil their responsibilities and ensure the effective implementation of this Policy within their speciality.

The **CMS manager** will support the HD Nurse Advisor

Clinical Staff have a responsibility for ensuring this policy is carried out to the benefit of people using the service.

Definitions

PwHD: Person with HD

PHDS: Plymouth Huntington Disease Service

MCA: Mental Capacity Act (2005)

FACE documentation: Single assessment process documents

Care Programme Approach (CPA) Policy and Standards: Local policy outlining National framework for Care Planning.

H.D.A: Huntington's Disease Association

RCA: Regional Care Advisor (H.D.A.)

NSF: National Service Framework

CRT: Central Referral Team, a local service

POVA: Protection of Vulnerable Adults

Service Objectives

To support individuals affected by HD, whether they have the gene, are 'at risk' of having the gene or are living with someone with the gene, in a manner which is person centred, and respects their individual needs, treating the person with respect, dignity, and ensuring privacy.

To provide a service Monday – Friday, from 9.00 a.m. – 5.00 p.m. – ensuring that all individuals and families have access to emergency numbers outside these hours.

Offering regular reviews and assessments, regular out-patient appointments, ongoing monitoring, individual and group support, formal and informal education for families and professionals, carers support, research opportunities, referrals to other health professionals and telephone support, advice, guidance, signposting.

To work towards the standards / recommendations in local and national policies, particularly the NSF for Long-Term neurological conditions (2005).

Maintain and develop effective working relationships with service users, carers and care co-ordinators, statutory and non statutory agencies, especially the H.D.A. Ensuring that relevant policies are adhered to, e.g. equality and diversity, risk management, protection of vulnerable adults, manual handling, complaints, to encourage independence, personal choice and to support people to function to their optimum level.

Adhere to the Care Programme Approach Policy and Standards.

Adhere to the Mental Capacity Act (2005).

Adhere to relevant NICE guidelines, particularly those related to mental health including, 'Depression in adults with a chronic physical health problem' (200?)

Adhere to NHS Plymouth medication policies, Safe and Secure Handling of Medicines v 5.10 and Non – Medical Prescribing.

Adhere to the Mental Health Act (1983), and amended 2008.

Adhere to standards laid down by the European Huntington Disease Network to ensure that Heathleigh remains as an accredited site to offer REGISTRY a Europe-wide observational HD study.

To continue to work with, and improve the experience of Carers.

To work within the policies relating to professional working e.g. lone working, and appropriate dress code and in line with professional Codes of Conduct, Trust Policies, Protocols and Guidance.

Referrals

Referrals can be made by any health or social care professional and should be made via the CRT. When accepting a referral the following information is

required from the referrer:

Name, date of birth and address

Hospital number and NHS number

Ethnicity, marital status

Assessment of current difficulties and HD status if available

Risk history and current risk assessment

Names and details of support provided by other services

Details if detained

Medication plan (if known to services) including:

Full details of current medication (including name of medicine, strength preparation and dosage/frequency) and any allergies/sensitivities to previous medication.

Self referrals are accepted and the Specialist HD Nurse will ensure the referral is put though the Central Referral Team.

Out of area referrals will be offered a one off appointment with the Specialist HD nurse for assessment and will be invited to attend Euro HD clinics if Plymouth is their most local clinic.

Case management

New referrals will be offered an appointment to discuss their needs. FACE or CPA documentation will be completed as appropriate, alongside a risk assessment and HoNOS. Assessments will focus on HD related issues, including, mood, dietary concerns, swallowing/choking risk, concerns re activities of daily living, including driving, falls risk, and whether POVA or MCA should be applied.

If there is a clear role for the PHDS, CPA or a Statement of Care will be commenced. Wherever possible, the Care Plan or Statement of Care will be formulated and jointly agreed by the PwHD, family where appropriate and the Specialist HD Nurse. This will usually offer a time limited intervention or 6 monthly reviews. If no further intervention is required a single contact will be entered on SystmOne as per CPA policy.

An episode will be opened to the Specialist HD Nurse whilst there is a clear plan for an intervention. The plan will be written in a Statement of Care or CPA care plan as appropriate. The Specialist HD Nurse will be the Care co-ordinator or lead professional, as appropriate.

In line with the CPA policy individuals on Standard Care will not always have a Consultant episode open. An appointment will be made for the individual to see the Consultant if required.

Individuals on the Specialist HD nurse case load will be seen at least 6 monthly, reviews will be completed at this time in line with CPA/Standard Care policy.

If an individual is not being actively managed by the Specialist HD nurse, but requires ongoing monitoring they will continue to have an Episode open to the Consultant and receive an annual Out Patient Appointment and/or Home Visit and an alternating 6 monthly Euro HD assessment or two OPAs/HVs as appropriate.

Each person using the PHDS will be referred for an assessment by an Occupational Therapist, Physiotherapist and/or Speech and Language Therapist if required. Referrals might also be made to the Dietician, Psychologist, or other Professional.

The Specialist HD Nurse will participate in all relevant CPA and Health care records audits.

Individuals only participating in Euro HD will only have an episode open to The HD Specialist Nurse Advisor as the Principal Investigator for this study.

In the case of a CHC checklist being completed, the HD Specialist Nurse will complete a full assessment and the DST. If the person is eligible for CHC funding the Specialist HD nurse will remain as the CHC care co-ordinator and the individual will stay on Standard care or CPA as appropriate. Any Best Interest or POVA meetings will be chaired by the Specialist HD Advisor.

All contacts and activity will be recorded on SystmOne.

Discharge from Service

Individuals who do not wish to be followed up for 6 monthly reviews will be discharged. An individual who does not attend 3 out patient appointments (including Euro HD appointments) or cancels 3 Home Visit reviews will be discharged with the proviso that they can be re-referred at anytime if there is an HD related issue. If the Consultant or HD Specialist Nurse is concerned for their safety these concerns will be addressed and a plan agreed.

Individuals in Nursing Homes or other full-time care will be discharged, once the PHDS has offered support in maintaining appropriate activity and any training required, with the proviso that they can be re-referred at anytime if there is an HD

related issue.

Patients under the care of Adult Mental Health CPNs will be discharged to them with the proviso that they can be re-referred at anytime if there is an HD related issue.

Confidentiality

PHDS will adhere to the Trust's Confidentiality Policy and all Data Protection legislation in accordance with the Data Protection Act.

Mental Health Act 1983

The Specialist HD Nurse would not normally have patients who are detained under the Mental Health Act on their caseload, but would support ward staff with training and advice if required.

For those persons entitled to section 117 aftercare, a section 117 planning meeting should be held prior to discharge from the Ward, although this may not take place until after an extended period of leave. The Specialist HD Nurse would be part of this meeting. It is probable that the PwHD would stay with the Adult Mental Health services due to the complexity of their service needs.

Mental Capacity Act (2005)

This Act provides a statutory framework to empower and protect people who may lack capacity to make some decisions for themselves.

The Specialist HD Nurse is aware of the five statutory principles contained within the legislation and the legislation's requirements for assessing capacity.

The Specialist HD Nurse is aware of the circumstances in which they are lawfully required to contact the Independent Mental Capacity Advocate, the IMCAs role and how to access them.

The Specialist HD Nurse will ensure that the individual is aware of their right to make advance decisions regarding the refusal of care or their right to make a lasting power of attorney relating to welfare decisions.

The Specialist HD Nurse Advisor will chair Best Interest meetings if the person is being cared for under Continuing Health Care.

Mechanisms for on-going Service User / Carer Feedback / Involvement

The Specialist HD Nurse ensures that an annual questionnaire is sent out to everyone using the service in January of each year in line with Livewell Southwest's policy.

Leaflets are available to ensure individuals know how to make a complaint about the service and about PALS and how to contact them.

Communication

PHDS can be contacted by telephone on 01752 435363

To enhance communication the Specialist HD Nurse and the HD Specialist Nurse Advisor meet on Monday morning to discuss caseload and referrals.

Medication Management

The GP will be advised of any changes to medication by detailed letter written by the Dr or as a minimum a standard letter – see Appendix 1

Referrals to other Agencies

The Specialist HD Nurse will complete referrals to the appropriate professional (see Care Programme Approach Policy and Standards) using eCPA paperwork and a telephone message will be left advising the appropriate care co-ordinator that there is a referral on eCPA. Referrals to other agencies such as; social care, day therapy and psychology will be completed on an individual basis.

Workforce Developments

The Specialist HD Nurse will carry a caseload and will be Care co-ordinator or lead nurse for any patient on their case load. They will be responsible to ensure assessments are completed in line with the CPA/ Standard Care policy and that people using the service are reviewed 6 monthly.

The Specialist HD Nurse Advisor is responsible for regular line-management and case-load supervision as per Trust Policy. They will act as an advisor and quality monitor.

Supervision and Line Management

All Staff are offered clinical supervision. Clinical supervision must be received in accordance with the Trust's policy on Clinical Supervision.

Line management will be provided adhering to the organisations's Appraisal and Management Supervision Policy.

All Staff will receive an annual Appraisal in accordance with the organisation's policy (Appraisal for Staff Policy).

Training

All staff receive mandatory, essential and other appropriate in-service training, to update their skills and knowledge base.

The PHDS can offer a placement or learning to members of the multi-disciplinary team.

Management of Violence

Livewell Southwest operates a zero tolerance policy for violence and aggression. This does not allow verbal abuse threats or physical violence towards anyone or damage to property. A breach of this may result in police involvement.

See Management of Violence Policy on the PCT website at www.plymouthpct.nhs.uk

Smoking

The Mount Gould Hospital Site is smoke free. Service Users, Visitors and Staff are not allowed to smoke in the Unit or grounds. There is a designated smoking area for the Clinics for the use of patients only.

Comments / Complaints and Compliments

Posters are placed around the clinic identifying how to make a comment, complaint or compliment.

Monitoring Compliance and Effectiveness

Livewell Southwest will monitor and review this policy in partnership to ensure we are meeting the aims / objectives of the policy. The compliance and review processes will include:

Annual update of Information / leaflets.

On-going review of progress against NSF for long-term neurological conditions – see appendix B

Updating of policy in light of significant changes to Livewell Southwest wide policies / protocols for example:

CPA policy

Management of Violence Policy

Other recommendations affecting community care

Incorporation of feedback from local patient satisfaction surveys

All policies are required to be electronically signed by the Lead Director. Proof of the electronic signature is stored in the policies database.

The Lead Director approves this document and any attached appendices. For operational policies this will be the Locality Manager.

The Executive signature is subject to the understanding that the policy owner has followed the organisation process for policy Ratification.

Signed: Director of Operations

Date: 10th May 2016

Appendix 1

Plymouth Community Memory Service

stages of dementia
The development of the dementias over the arc of the illness.
Possible course 0-10+ years.

Stage 1.

Will include anxiety about memory problems, mild cognitive impairment (MCI), minimal and mild dementia.
Behavioural range:

Increased misplacing of possession, minor/variable errors in orientation, some blunting in capacity to follow reasoned argument and to solve problems, occasional errors in familiar tasks. Fully self caring. Still driving. Managing finances. Language intact.
Difficulty with new information and recent events. Belongings lost. Recently imparted information intermittently forgotten or totally lost. Orientation inconsistent. Obvious problems with new activities or those which demand problem solving or reasoning. Some word finding difficulties but social language fluent. Would not be asset in pub quiz team- starting to lose names of politicians, capitals events.
Still doing household chores/cooking but not to same standard/repertoire. Less coherent dressing e.g. colour coordination. Change in emotional responses. Still doing hobbies. Medication compliant independently/with support e.g. dosette, blister pack.
No obvious 'psychiatric symptoms'
Measures: HONOS 0-7.
Cluster 18
MMSE 30-20
Bristol Activities of Daily Living (BADLS) 0-10
HADS 0-7

Stage 2.

Behavioural range:

Big problems with retention/retrieval of new information. Recent events transiently recalled or forgotten. Problems accessing personal history. Confabulation. Orientation impaired. Reasoning compromised. Questions about their persons capacity to make decisions about finances and safety are frequently raised. Language shows obvious changes. ADL and community living skills need support e.g. shopping, housework, finances. Dressing and meals may

cause concern. Self care/personal hygiene compromised. Not safety aware. Possible memory disasters. Would not remember appointments/arrangements. ACI meds prescribed/considered. Medicines need direct prompting/administration Problems in multiple parameters are obvious. Possible psychiatric symptoms. Personality changes. Possible aggression.
Measures: HONOS 7+
Cluster 19
MMSE 20- 10
BADLS 10+

Phase 3.

Behavioural range:

Remote /episodic memory severely impaired. No new information, learning or recent experiences retained. Not orientated for time place. May not recognise very familiar people. Not able to problem solve or reason. Needs prompts and guidance for all self care and ADL activities. Not aware of personal safety. Problems with expression and comprehension. Unlikely to have capacity for most decisions. Emotional poverty. Unable to initiate activities. Incontinence. Mobility reduced. Purposeless walking. ACI meds stopped Psychiatric symptoms.
Measures: HONOS 7+
Cluster 20
MMSE 15 or less
BADLS 10+

Phase 4.

MMSE 10 or less. Cluster 21
Intensification of all the above. Language may be reduced to simple phrases or single words.
Circadian rhythm may be profoundly disturbed. Extreme apathy and exhaustion is seen. Likely to need help with feeding- basic motor functions e.g. chewing and swallowing may be impaired as expression of extreme apraxia. Motor disturbances e.g. rigidity/primitive reflexes may interfere with provision of nursing support. Snouting and grasping reactions seen. Myoclonic and epileptic seizures may be present.
Most frequent cause of death pneumonia followed by MI and septicaemia.

Appendix B

Service plan in relation to NSF for Long-term Neurological Conditions

1 A person centred Service

Tier 1-

- Team arrange appointment or visit and complete FACE Background Information Form (BIF)
- Assess risk using TAG or CPA assessment as appropriate
- Team give information sheets as required (e.g. HDA, PCT, SS etc) to promote self management and information about Euro HD to promote positive participation in research if interested

Tier 2 -

- If indicated formally assess mental health and complete standard care letter or CPA documentation or offer Out Patient Appointment

Tier 3 – case management

- If required complete Integrated assessment - health and social care staff complete FACE overview and care plans indicating contingency plan and environmental, social aspects - to be reviewed regularly and referrals made as clinically indicated
- Regular reviews will be planned, to monitor all aspects of HD including mood, behaviour, weight, swallowing or choking difficulties, speech difficulties, changes in mobility and posture and discuss difficult issues including driving, lasting power of attorney and advance decisions in a timely fashion.
- Depression, which is common, will be addressed initially with the GP using NICE guideline 91 – 'Depression in adults with a chronic physical health problem'

2. Early Recognition, prompt diagnosis, and treatment

- Referrals to consultant psychiatrist will be made promptly for psychiatric assessment and individuals will be referred to a Neurologist if required.
- Information provided to GPs on how to refer and to whom – flow chart – Heathleigh team to lead in discussion with Neurologist and Genetics

3. Emergency and acute management

- Team to attend Derriford asap after person with HD admitted to assist with assessment and care planning. Provide information as required and regular visits.

4. Early and Specialist rehabilitation

- Individuals will be referred to Physiotherapy and Occupational Therapy staff early in the disease process to ensure they receive timely, ongoing

and high quality rehabilitation services to meet their continuing and changing needs.

5. Community rehabilitation and support

- People with HD will be referred for further assessments to Physiotherapy and Occupational Therapy staff to support them in meeting their continuing and changing needs and help them live as they wish.
- Heathleigh team to refer to Speech and Language Therapists, dietetics, psychology, art therapy etc as required
- Heathleigh staff to use tools, including Talking Mats to ensure individuals are able to participate and contribute fully in their care in order to increase independence and autonomy
- Specific groups will be provided for people with HD to educate and equip them for HD related challenges, to maintain wellbeing and abilities, and for peer support as required

6. Vocational Rehabilitation

- Team to contact Job Centre Plus to talk to Disability Advisors
- Staff to support individuals in work, with advice for employer or signposting if required

7. Providing equipment and accommodation

- Team to be actively involved in supporting individuals in their own homes to support them to live independently and maintain their health as per care plan
- Team to be actively involved in supporting individuals in residential placements to access appropriate support and equipment to maintain their health and quality of life if requested.
- Team to contribute to discussions with long-term conditions adaptations team to ensure needs related to HD are appropriately addressed

8. Providing personal care and support

- Team to provide support to home care teams in writing and carrying out comprehensive care plans
- Team to support individuals with life story work and/or communication packs in preparation for future needs

9. Palliative care

- Team to work with palliative care team and families to ensure that personal, social, spiritual, and psychological support are provided

10. Supporting families and carers

- Team will ensure that carers assessments are completed and regularly reviewed and that carers are registered with the carer support team and have up-to-date care plans

- Staff will give carers information about carers groups and refer for help with accessing them, or accessing a sitting service if required.
- Staff will ensure families have information about the HDA Regional Care Advisor
- Staff will provide formal and informal training opportunities for carers or family members

11. Caring for people with neurological conditions in hospital or other health and social care settings

- Team will work with teams in any setting used by people with HD to ensure their specific neurological needs are met.
- Team will continue to provide specialised training on a regular basis to carers in the statutory and non statutory sectors across Plymouth and ad hoc training as required.