

Service Specification No.	<b>02/GMS/0030</b>
Service	<b>ADULT EPILEPSY SERVICE</b>
Commissioner Leads	<b>CCP for General Medical and Surgical</b>
Provider Lead	<b>POOLE HOSPITAL NHS FOUNDATION TRUST</b>
Period	<b>1 April 2013 to 31 March 2014</b>

### 1.1 Aims

The aims of the service are:

To provide an epilepsy service for Dorset residents with strong links to primary and social care.

- To ensure timely referral, initial contact and diagnosis of adults with newly diagnosed epilepsy
- To deliver a quality service in line with NICE requirements
- To establish a Helpline for users and carers
- To ensure information and advice is readily available to users, carers and the wider community in a range of formats
- To further develop integrated care pathways and appropriate documentation
- To develop within the integrated pathway a known point of contact for each individual
- To improve the patients quality of life by facilitating access to services which enable patients to self manage and reduce the need for medical intervention
- To ensure individual patients have a care plan jointly developed and agreed with them. This should be communicated to primary care and should include an escalation plan, if appropriate, to inform out of hours service and the ambulance service.
- The care plan must include an action plan to support self care that has been jointly agreed with the patient and/or carers and should help patients to develop the necessary skills to be active self-managers
- To develop services within appropriate settings which offer convenient access for patients where possible;
- To make best use of support available across health and social care;
- To develop the role of the Epilepsy Specialist nurses to support people with epilepsy and staff working with people with epilepsy in Dorset

### 1.2 Evidence Base

In developing this service specification the Commissioner(s) have drawn on advice and guidance provided in the NICE Guidance CG 20 2004 on "The epilepsies: diagnosis and management of the epilepsies in adults in primary and secondary care". In addition the National Service Framework for Long Term Conditions published in March 2005 by the Department of Health has been considered. This National Service Framework (NSF) aims to transform the way health and social care services support people to live with all long-term neurological conditions. The NSF has 11 Quality Requirements. Key themes are early assessment and diagnosis, specialist input, independent living, care planned around the needs and choices of the individual, easier, timely access to services and joint working across all agencies and disciplines involved. It applies to all health and social services who are working with local agencies involved in supporting people to live independently, such as providers of transport, housing, employment, education, benefits and pensions.

The commissioners have also considered the guidance from the national event "Commissioning Epilepsy Services" February 2010 particularly relating to Learning Disability services.

Many of the Quality Requirements will be supported through the commissioning of this service.

### 1.3 General Overview

The objective is to commission a service that is compliant with NICE guidance to enable the

diagnosis, assessment, treatment and support of adults with epilepsy registered with a NHS Bournemouth and Poole or NHS Dorset based General Practitioner.

#### 1.4 **Expected Outcomes**

The performance of the service by the providers shall be monitored in terms of the following indicators, where such information is available.

##### **Clinical outcomes:**

- % managed on monotherapy
- % on combination therapy
- % seizure free in last 12 months
- Number of tertiary referrals converted to epilepsy surgery and reason why not converted if referred.
- % with care plans, including self care action plan

##### **Other outcomes:**

- New to Follow Up ratio on outpatient appointments, where available
- Waiting times;
- Number of new patients seen in the service;
- Number of patients referred to tertiary services for epilepsy surgery and reasons for not undergoing surgery, if referred
- Number of patients handed back to primary care for on-going review
- Serious/Adverse Incidents numbers.

##### **Quality of Life Outcomes:**

- Annual patient satisfaction survey responses;
- % of patients who feel in control of their epilepsy

#### 2.1 **Service Description**

This pan-Dorset Epilepsy Service is commissioned for all people over the age of eighteen who are registered with a NHS Dorset or NHS Bournemouth and Poole General Practitioner. People between 16 and 18 years of age who otherwise meet these criteria may be appropriate if they are no longer in full time education.

The service currently provides diagnosis, assessments, management, support and treatment to adults with epilepsy. The overall aim of the service is to enable people with epilepsy to overcome their activity limitations, to promote autonomy and participation and to facilitate psychosocial adaptation to their condition. The medical and nursing team promotes the biopsychosocial model of care. This is achieved by supporting the individual and family/carer in the process of adapting to their circumstances through the provision of appropriate interventions, information and advice, and acting as a resource for other health and social care professionals. The team aims to work closely in partnership across health and social care to facilitate this.

The service is intended to support collaborative specialist management for specific areas such as pre-pregnancy planning, pregnancy and requests to stop medication.

The Dorset Epilepsy Service has met with service users and carers to understand what they would like to see within a service. They have established a user and carer helpline and developed protocols for referral into the service (Appendix A). They are developing information sources and a database for all users of the service. A clinical protocol for adults presenting with presumed first seizure has been developed and agreed (Appendix B). Clinical guidelines and algorithms for other areas, including drug refractory epilepsy and status epilepticus are being developed.

The establishment of clear transition arrangements from children into the Dorset Epilepsy Service will need to be developed in line with generic transition principles for all children.

The adult Dorset Epilepsy Service is part of the Neurology services provided at all acute providers across Dorset by the Poole Hospital NHS Foundation Trust.

## **2.2 Accessibility/acceptability**

Any new patient referred to the service will be seen and have an initial assessment within 2 weeks of the date of the receipt of an urgent referral for new onset unprovoked seizure. If there is insufficient capacity for the patient to be seen in a clinic setting then the initial assessment may be undertaken by other means.

Any new patient referred to the service with an established diagnosis of epilepsy will be seen and have an initial assessment within the prevailing RTT time. For urgent referrals of patients with an established diagnosis of epilepsy, an appointment for the next available clinic will be made on receipt. Referrals which do not meet the criteria for review in the Epilepsy clinic, or there is insufficient clinical information provided will be discussed with the referrer.

## **2.3 Whole System Relationships**

### **Onward Referrals**

The service shall refer patients thought to be suitable for epilepsy surgery, within the appropriate guidelines, to the regional provider. Patients who have problems other than epilepsy will be referred back to their general practitioner with suggestions about further referral or treatment if necessary in line with local policy. Patients suspected to have cancer may be referred on directly. Patients receiving ongoing care from the service who require additional input from other specialties will be referred back to their GP in line with local policy.

### **Communications with Referrers**

The service shall confirm in writing, by fax or secure e-mail receipt of all referrals for suspected first seizures to the original source indicating the action taken or to be taken.

The Provider shall confirm in writing, by fax or secure e-mail the discharge of patients to the GP, consultant and/or original referral source indicating the management plan agreed with the patient or appropriate guardian.

In all cases, the Provider communications in respect of individual patients, should be copied to the patient's GP.

## **2.4 Interdependencies**

### **Expectations regarding partnership working**

The service shall establish and maintain contact, communication links and appropriate clinical arrangements with appropriate clinical colleagues working across primary and secondary care.

Effective shared responsibility with the Learning Disability services for the joint management of Learning Disability patients with epilepsy will be developed.

The service shall establish appropriate knowledge of the support available to patients and carers from Social Services, the NHS and/or the voluntary sector and provide guidance and advice to patients to enable them to access services.

The service shall establish and maintain contact and effective communication with appropriate social care colleagues to facilitate the above.

### **Communication with Patients**

The service will compile and provide to patients a Patient Information Leaflet, in a form to be approved by the Commissioner(s) providing appropriate information relating to the service and the Poole Hospital NHS Foundation Trust including information on complaints procedures.

The service will ensure that all communications relating to the care and treatment of patients are copied to the patient in accordance with current NHS policy and procedures.

## **2.5 Relevant networks and screening programmes**

The Commissioner(s) shall monitor the Performance of the Provider in meeting the service specification. This monitoring will encompass:

- The Poole Hospital NHS Foundation Trust monthly monitoring meetings

- Participation in the Epilepsy Sub-Group with updates, when required, to the pan Dorset Long Term Conditions Neurological Local Implementation Team.
- An annual review of survey questionnaires completed by patients.

### **3.1 Service model**

#### **Details of Service to be provided**

- The service will be available during normal working hours Monday to Friday every week of the year.
- Outpatient clinics for patients with a presumed first seizure will be provided at all the acute Trusts as part of the pan-Dorset Neurology services provision (Appendix B). Outpatient clinics for patients with non-complex epilepsy will be held at all acute Trusts as part of the pan-Dorset Neurology service provision.
- Outpatient clinics for patients with complex epilepsy will be provided at all acute Trusts visited by a Consultant Neurologist specialising in epilepsy with appropriate specialist clinic provision. Such clinics will be organised to provide sufficient time for full clinical assessment as well as access to investigations including neurophysiology and high quality MRI where appropriate.
- Emergency service cover will be provided via the acute provider units where clinically necessary. Protocols have been agreed for onward referrals ongoing and management to the Dorset Epilepsy Service for presumed first seizures.
- Clinical protocols will be developed for patients with established epilepsy, drug refractory epilepsy and status epilepticus.
- A single point of contact for referral has been established for the Dorset Epilepsy Service based in Poole. Contact by letter, e-mail, fax or telephone is provided for. Details are signposted in documentation from the Dorset Epilepsy Service and in appropriate electronic resources.
- The hours of operation of the service will be signposted and mechanisms put in place to record all telephone contacts;
- The specialist nurses will provide a biopsychosocial assessment which considers, amongst other areas; the employment, social care needs and driving status needs of the patient and works to ensure access to the best level of services.

### **3.2 Care Pathways**

- The Dorset Epilepsy Service, working through the Epilepsy Sub-group, are developing care pathways to support this service. These pathways will have multi sector/ multi agency input . These will include established epilepsy, suspected first seizure, refractory epilepsy and status epilepticus to be agreed during 2011-12

### **4.1 Geographic coverage/boundaries**

Pan-Dorset service provision for all adult patients registered with an NHS Bournemouth and Poole or NHS Dorset General Practitioner.

### **4.2 Location(s) of Service Delivery**

Outpatient clinics at acute providers across Dorset

Inpatient services at Poole Hospital NHS Foundation Trust

Emergency service cover will be provided via the acute provider units with agreed protocols for the ongoing management and onward referrals to the Dorset Epilepsy Service

Community clinics and settings where appropriate

### **4.3 Days/Hours of operation**

- The service will be available during normal working hours Monday to Friday every week of

the year

- Outpatient clinics will be provided at the acute providers as part of the pan-Dorset Neurology services provision
- A single point of contact to be available for referral.
- The Helpline service will provide details of the hours of operation of the service and have mechanisms to answer and record all contacts;

#### **4.4 Referral criteria & sources**

##### **Consultant Referral Criteria**

- Adult patients registered with a local GP who have a suspected diagnosis of epilepsy who meet the agreed referral criteria
- Adult patients with an established diagnosis of epilepsy with intractable epilepsy requiring specialist input
- Adult patients referred with an established diagnosis of epilepsy following review by an Epilepsy Specialist Nurse if clinically required only

##### **Specialist Nurse Referral Criteria**

- Adult patients with an established diagnosis of epilepsy which has previously been diagnosed by a Neurologist who has been discharged from Neurological follow-up. In such a case the Consultant Neurologist should agree to provide overall clinical supervision of the Epilepsy Specialist Nurses.
- Adult patients who are under the continuing care of a Consultant Neurologist who have a confirmed diagnosis of epilepsy.

The Dorset Epilepsy Service shall reject any referral received for patients not considered appropriate for this service. Any cases of dispute should be discussed with the commissioners.

##### **Sources of Referrals**

The services shall be accessed by all appropriate' referrals from:

- NHS Bournemouth and Poole and NHS Dorset General Practitioners
- Emergency & Secondary Care Doctors
- Learning Disability Doctors
- Mental Health Doctors

The service will also accept self referrals of individuals who are already known to the service providing these individuals meet the referral criteria as above or their medication requires review in the view of the referrer

#### **4.5 Referral route**

- A single point of contact to be available for referral.
- The hours of operation of the service and that mechanisms to answer and record all telephone contacts.

#### **4.6 Exclusion criteria**

Any new patient referred to the service with seizures in the context of significant drug or alcohol misuse, where either intoxication or withdrawal is likely to be responsible for their seizures should first be referred to the appropriate local drug & alcohol service. If there are ongoing seizures despite abstinence then re-referral to the service would be appropriate.

Providers shall reject any referral received for patients not considered appropriate for this service on clinical grounds. Any cases of dispute should be discussed with the commissioners.

#### **4.7 Response time and detail and prioritisation**

Any new patient referred to the service will have an initial assessment within 2 weeks of the date of the receipt of urgent referral for new onset unprovoked seizure as part of the pan-Dorset

Neurology services provision. If there is insufficient capacity for the patient to be seen in a clinic setting then the initial assessment may be undertaken by other means (Appendix B).

Any new patient referred to the service with an established diagnosis of epilepsy will be seen and have an initial assessment within the prevailing RTT time. For urgent referrals of patients with an established diagnosis of epilepsy, an appointment for the next available clinic will be made on receipt. Patients with complex epilepsy will be given appointments in a specialist epilepsy clinic with sufficient time to allow full assessment.

Any known patient re-referred to the Provider due to deterioration in their condition, will be offered an appointment based on their clinical need and with the agreement of the referrer.

- Effective hand back of appropriate patients to GPs to facilitate care closer to home
- Effective sign-posting to a range of health and social care provision

The principles of self care by the patient will be promoted at every opportunity in order that the patient feels in control of their epilepsy.

**Patient and Carer Information**

- A Telephone Helpline for patient and carer information and support
- Written care plan and information in range of formats/styles. The written care supports self care and self management. Where appropriate it should include rescue medication processes
- Links to national Epilepsy Action third sector organisations
- Developing and improving support in the community

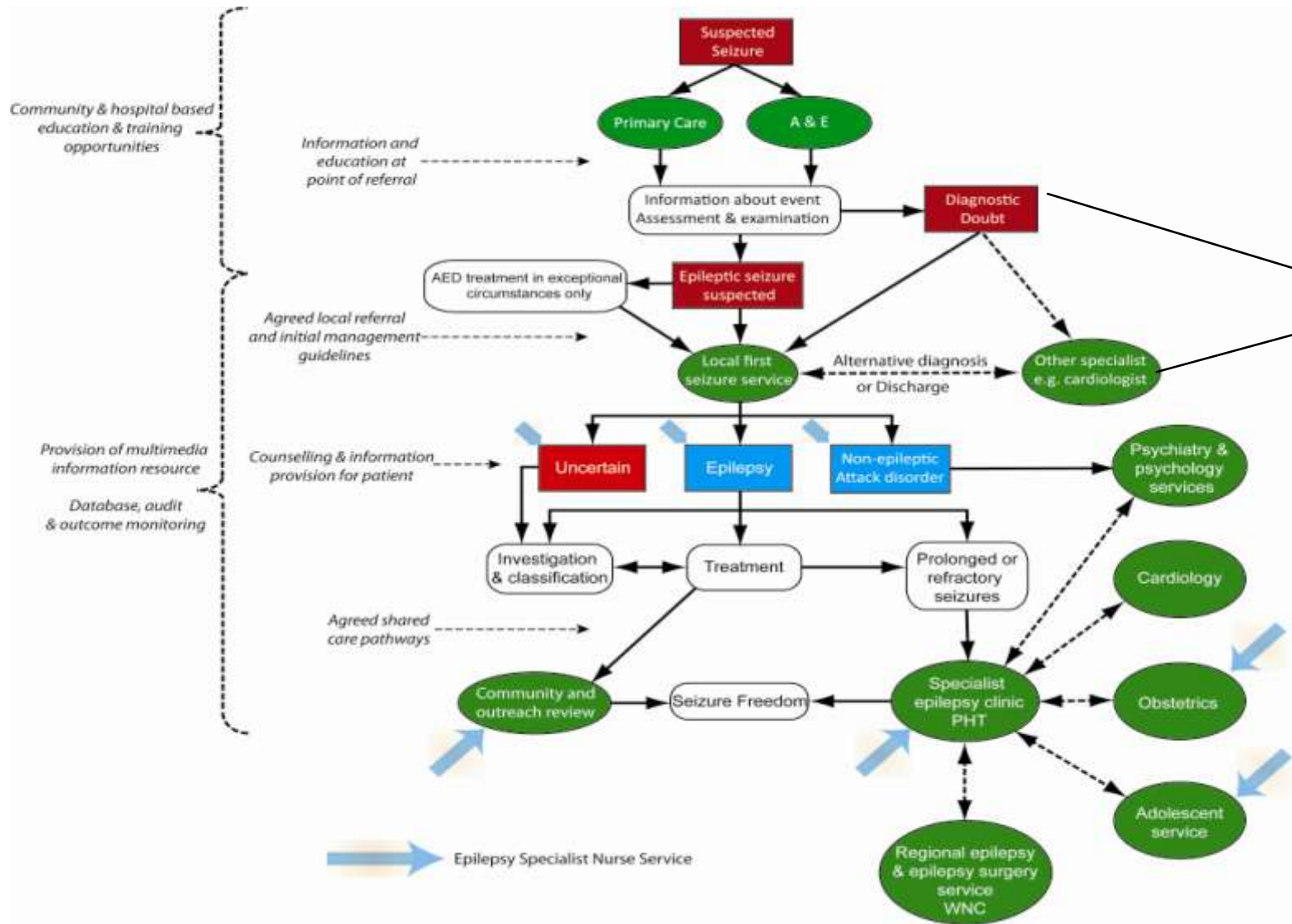
**4.8 Prescribing**

Prescribing will be in line with the joint formulary between primary and secondary care with first line drugs being the first choice to prescribe

<b>5.0 Performance indicator</b>	<b>Indicator</b>	<b>Threshold</b>	<b>Method of measurement</b>	<b>Consequence of breach</b>
<i>Quality</i>				
	% managed on monotherapy	Less than 30% of patients managed on monotherapy	Quarterly audit	Report CMM
	% on combination therapy	Over 50% of patients managed on combination therapy Over 5% on triple therapy	Quarterly audit	Report CMM
	% seizure free in last 12 months	25% or less seizure free in the last 12 months	Annual audit	
	% with care plans, including self care action plan	85% or less	Annual audit ? to be backed up with evidence from the patient satisfaction survey	

<b>5.0 Performance indicator</b>	<b>Indicator</b>	<b>Threshold</b>	<b>Method of measurement</b>	<b>Consequence of breach</b>
	Number of serious/ Adverse incident numbers	All incidents to be reported	Via the Quality Monitoring processes	
	Annual patient satisfaction survey response, to include % of patient who feel in greater control of their condition		Annual audit report to QMM and Epilepsy sub-group	
<b>Performance and productivity</b>				
Activity levels	Number of new patients seen in service. To be reported by PCT	To be agreed once baseline activity established	Quarterly review	
	Number of patients handed back to primary care for on-going review	To be agreed once baseline activity established	Quarterly review	
	Number of tertiary referrals converted to epilepsy surgery and reason why not converted if referred	To be agreed once baseline activity established	Quarterly review	
	First seizure waiting times within 2 weeks. To be reported by PCT	100%	Monthly report	

## Appendix A: Dorset Epilepsy Service Referral Routes & Protocol Outlines





### **First Seizure Clinic Referrals:**

#### **1. Aims:**

- 1.1. Intention to review all patients thought to have a first unprovoked seizure within 2 weeks of referral and provide prompt and appropriate management, in line with established NICE guidance.

#### **2. Referral Criteria:**

- 2.1. The referral should include sufficient clinical information where this is available. Referrals may not be accepted if there is insufficient information.
- 2.2. Patients should have provoking causes excluded before referral. Patients would usually have had a normal 12-lead ECG and normal baseline blood tests including FBC, ESR ( $\pm$ CRP), U&E's, LFT's,  $Ca^{2+}$ ,  $Mg^{2+}$ , Glucose.
- 2.3. Head injuries complicated by seizures should first be managed through the existing head injury service.
- 2.4. Patients with seizures in the context of significant alcohol misuse will not normally be seen in the Dorset Epilepsy Service unless they have been abstinent for at least 3 months. You may wish to check serum gamma GT ( $\pm$  blood alcohol level) if there is clinical doubt.

#### **3. Referral Process:**

- 3.1. The referral form can be completed electronically (where available) or on paper. Referrals by letter are also acceptable, but MUST contain all the required information (see Appendix A – Referral Guideline). All referrals should be sent to the Dorset Epilepsy Service in Poole (via EPR, secure email, fax or post) and appointments will then be arranged with a Neurologist as local to the patient as possible.
- 3.2. Referrals must come from a qualified doctor and this would normally be either through emergency medicine or general practice.
- 3.3. Patients whose registered general practitioner is outside the county of Dorset should be directed to their local service, via their usual general practitioner.
- 3.4. The initial patient review by the Dorset Epilepsy Service may be in clinic, as a ward review or by telephone consultation.
- 3.5. Initial contact may be with one of the Epilepsy Specialist Nurse team, but all patients referred to the first seizure referral service will be reviewed by a Neurologist (ideally an Epilepsy Specialist) to establish or refute a diagnosis of epilepsy and try to further define the type of epilepsy (if appropriate).

#### **4. Investigations (After Referral):**

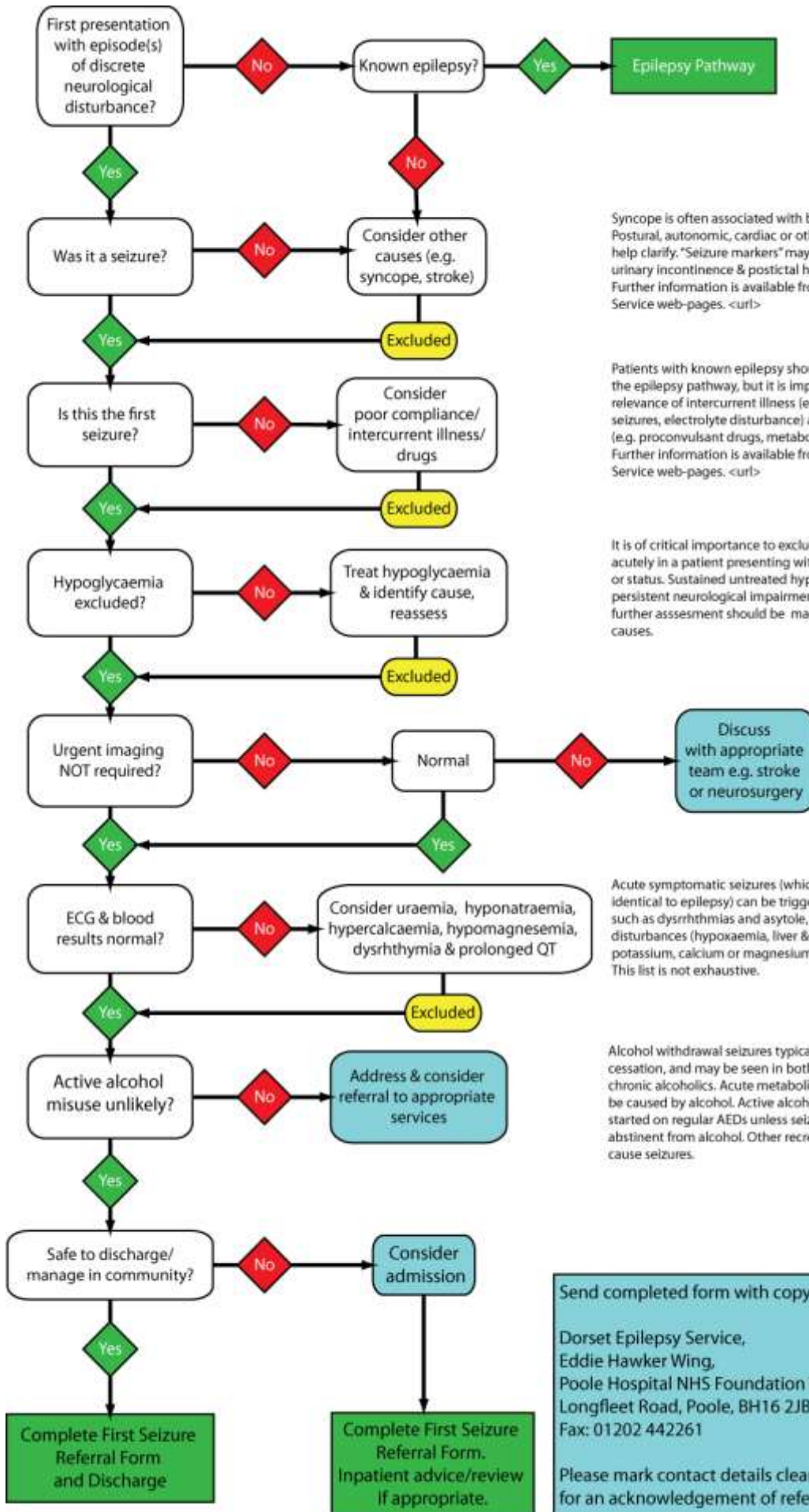
- 4.1. CT, MRI or EEG may be undertaken prior to review in certain circumstances, where this may help stratify risk of further seizures and hence guide treatment. If not clear from departmental protocols, investigations would normally be discussed with a Neurologist prior to request.
  - 4.1.1. All patients under the age of 70 years with unprovoked seizures will have a routine interictal EEG as part of the diagnostic work-up arranged by the Dorset Epilepsy Service.
  - 4.1.2. MRI (with epilepsy protocol) is the superior modality where imaging is indicated in patients with unprovoked seizures, and if appropriate this may be arranged prior to clinic review.
  - 4.1.3. Additional specific investigations for diagnosis may be arranged from clinic as appropriate.

#### **Outcomes:**

- 4.2. Patients not thought to have epilepsy will be discharged.
- 4.3. Patients believed to have epilepsy will be followed up by the Epilepsy Specialist Nurses, with input from the relevant Neurologist when & where appropriate.
- 4.4. Patients where the diagnosis of epilepsy is uncertain will be seen and followed up the Neurologist until such time as a diagnosis is clear or further neurological input is not required.
- 4.5. If medication is clinically appropriate, a tailored treatment plan (with a written copy for the patient) will be developed with the patient and a prescription provided from clinic on the understanding that further prescriptions will be provided by the patients usual general practitioner. Joint prescribing guidelines will be followed

- 4.6.** Oral & written information will be provided to the patient, including guidance on safety, medication, driving, pregnancy (where appropriate) and seeking further medical advice.
- 4.7.** In order to monitor outcomes & quality indicators, patients with epilepsy referred in to the service would generally be followed up for a period of around two years, or until such time as medication changes are stabilised. After this time patients will be discharged back to primary care for their annual reviews, with the expectation of referral back into the service promptly in the event of need.

Figure 1: Generic First Seizure algorithm



Syncopal is often associated with brief stiffening or jerking. Postural, autonomic, cardiac or other features/triggers may help clarify. "Seizure markers" may include: tongue biting, urinary incontinence & postictal headache/confusion. Further information is available from: Dorset Epilepsy Service web-pages. <url>

Patients with known epilepsy should be managed using the epilepsy pathway, but it is important to evaluate the relevance of intercurrent illness (e.g. acute symptomatic seizures, electrolyte disturbance) and current medication (e.g. proconvulsant drugs, metabolic side-effects) etc. Further information is available from: Dorset Epilepsy Service web-pages. <url>

It is of critical importance to exclude hypoglycaemia acutely in a patient presenting with a generalised seizure or status. Sustained untreated hypoglycaemia may lead to persistent neurological impairment (stroke). If identified, further assessment should be made for drug or endocrine causes.

Acute symptomatic seizures (which may look clinically identical to epilepsy) can be triggered by cardiac events, such as dysrhythmias and asystole, or by metabolic disturbances (hypoxaemia, liver & renal disease, sodium, potassium, calcium or magnesium abnormalities). This list is not exhaustive.

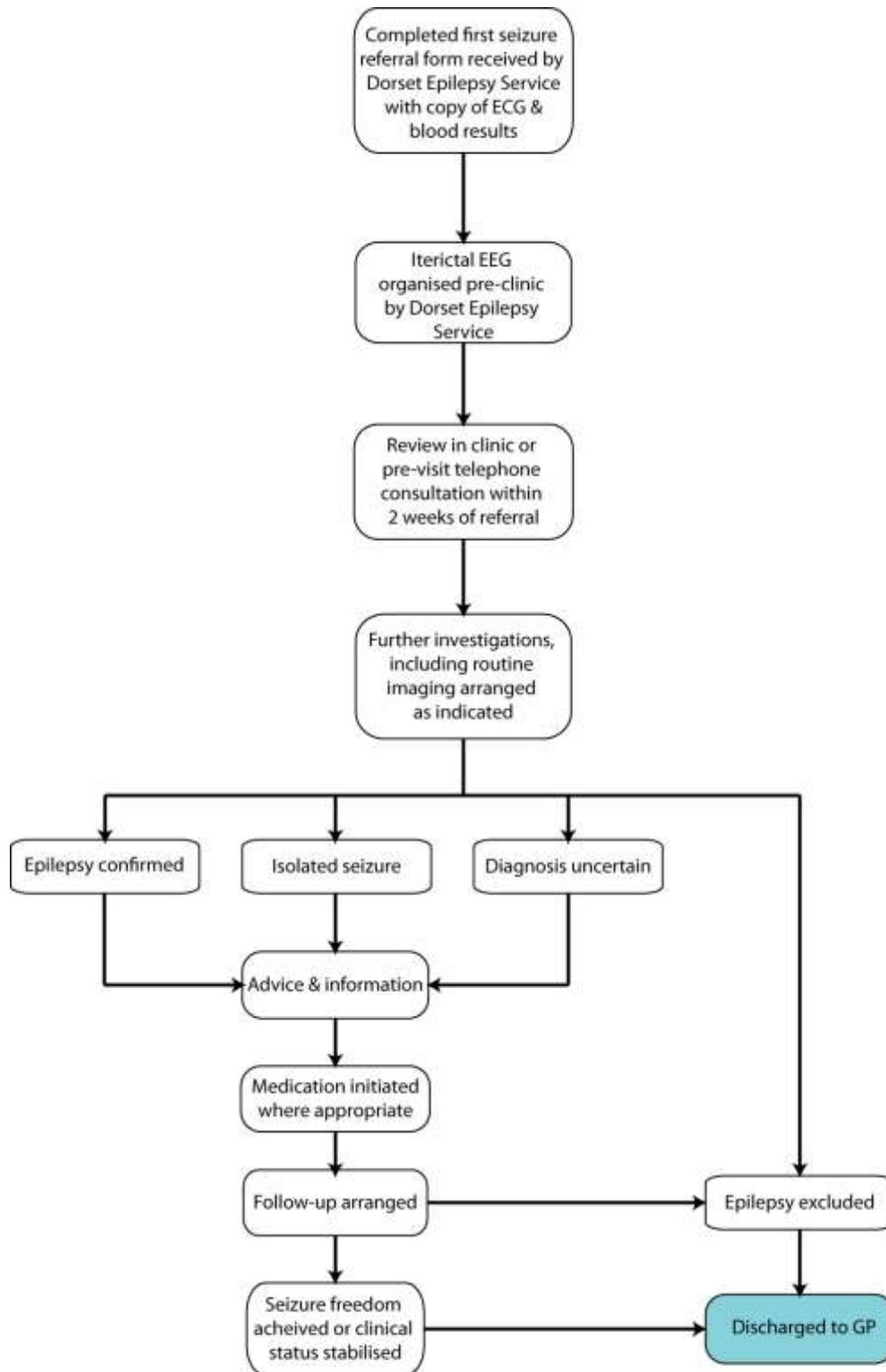
Alcohol withdrawal seizures typically occur 6-48hrs after cessation, and may be seen in both binge drinkers and chronic alcoholics. Acute metabolic disturbances may also be caused by alcohol. Active alcohol misusers are not usually started on regular AEDs unless seizures continue when abstinent from alcohol. Other recreational drugs may also cause seizures.

Send completed form with copy of ECG & blood results to:

Dorset Epilepsy Service,  
 Eddie Hawker Wing,  
 Poole Hospital NHS Foundation Trust,  
 Longfleet Road, Poole, BH16 2JB  
 Fax: 01202 442261

Please mark contact details clearly if you wish for an acknowledgement of referral.

Figure 2. First seizure referral pathway



Send completed form with copy of ECG & blood results to:  
Dorset Epilepsy Service, Eddie Hawker Wing, Poole Hospital NHS Foundation Trust,

## **Referral Guideline & Checklist for First Seizure Service**

### **1. Inclusion Criteria**

- 1.1. No pre-existing diagnosis of epilepsy. Patients with a prior diagnosis of epilepsy should be managed according to the refractory epilepsy pathway.
- 1.2. Normal ECG and routine blood tests. If these criteria are not met then other causes should be excluded first.
- 1.3. No significant head injury. If not met then patients should be initially managed through the existing head injury pathways.
- 1.4. Seizures not related to active alcohol misuse. Patients with seizures in the context of alcohol excess or acute withdrawal should be managed through existing alcohol services as appropriate.
- 1.5. Additional factors to be considered before making referral:
  - 1.5.1. New persistent focal neurology. Patients with seizures associated with new focal neurological features would normally be expected to be referred to the appropriate service (e.g. Stroke) first. Such patients may require admission and urgent inpatient investigation as clinically appropriate.
  - 1.5.2. Patient's GP is within Dorset area. Patients who are normally registered with GP's outside Dorset, or are only visiting the county should be referred to their local first seizure service.

### **2. Information requirements for appropriate referral:**

- 2.1. Completion of either the Dorset Epilepsy Service First Seizure Referral Form, or a referral letter including the following information:
  - 2.1.1. Patient demographic details, including preferred hospital, contact numbers & methods.
  - 2.1.2. Referrers contact details, grade/post and where confirmation of referral acceptance is to be sent. If not specified, confirmation will be sent to the referring doctor and registered GP.
  - 2.1.3. Clinical details of the attack(s) including:
    - 2.1.3.1. Date(s), whether witnessed or unwitnessed (and by whom if known).
    - 2.1.3.2. If witnessed, a description of attack including appearance of patient, duration, any focal ictal and post-ictal features in particular.
    - 2.1.3.3. Any possible provoking factors or triggers.
  - 2.1.4. Findings of general and neurological examination.
  - 2.1.5. Details of any investigations undertaken/requested, and results if available.
  - 2.1.6. Details of any treatment given, such as benzodiazepines or anticonvulsant drugs started.

### **3. Checklist for referral:**

- 3.1. Patient meets inclusion criteria.
- 3.2. All requested clinical details provided where available.
- 3.3. Copy of ECG and blood results to be attached to referral.