Non-oral treatment integrated pathway in Parkinson's
Using this ICP

This non-oral care pathway has been developed to help clinicians understand the route a person with Parkinson's may follow in order to receive non-oral therapy to manage the disease. It will support the decision making process to help understand which therapy the person should receive and then enable clinicians to understand the process for referral. The framework can then be customised for any locality.

Navigation

This ICP is an interactive pdf that you can easily navigate using the menu tabs above and tabs at the side. There are also links and icons in the pathway itself that you can use to navigate around the tool.

Summary

- **Overview pathway** shows a top level view of the whole pathway.
- **Pathway close-ups** zoom in on specific areas of the pathway, showing individual services and how they link together, and more information around what should happen, and why.

Icons throughout the pathway highlight where you can click to find more information -

- **Key performance indicators** (KPIs) are suggested for how to measure whether the pathway is working effectively. These are measurable elements in the pathway, either quantitative, (e.g. fewer emergency attendances), or qualitative (e.g. positive experiences reported through the friends and families test). Quality Indicators (QIs) are developed in partnership with clinicians and designed to be used for benchmarking and audit of services. A full range of QIs can be found on the HSCIC website.

- **Additional information** gives more detail on a specific part of the pathway - anything from national guidance to activity needed, to commissioning recommendations.

- **Governance policy** covers parts of the pathway that might benefit from, or are reliant on, specific governance structures being in place. This might include, for example, a specific group of professionals working as a team under one manager, or a particular formal working arrangement across health and social care professionals in one service.

- **Information provision** indicates particular information that a person with Parkinson's should receive at a point in the pathway. It is by no means exhaustive, but suggests important information at key times.
Action plan. At the end of this pathway are pages for you to outline what needs doing in your area to make sure you have your own advanced pathways in place. There is space to outline what needs doing and who will take the lead on doing this.

Accompanying documents covers any supporting information such as links to relevant policy documents, for example NICE Guidance, and any other local or national information that is relevant to the pathway. This section may be added to on a regular basis and should not be thought of as the only place to find relevant documents.

Printing
This ICP tool is designed to be interactive and to be used electronically. The pdf document itself is very large so you may want to select a page range before printing. If you would like to print the full integrated care pathway only, click on the print icon below.

Key

- Primary care
- Secondary care
- Tertiary care
- Specialist services
  - Assessment / re-assessment
  - line of referral
  - Input into
  - Good working link with information provision
  - Close up of pathway
  - Guidance or brief information
Acknowledgements

This clinical pathway has been developed with guidance from a steering group which included movement disorders specialists, Parkinson’s UK and neurological services commissioners.

AbbVie, Britannia and Medtronic have reviewed the pathway to ensure that it is accurately reflects current practice and is in line with the licences of their marketed medicines and devices.

AbbVie, Britannia and Medtronic have contributed financially to the development of this pathway. The original Parkinson’s integrated care pathway was developed with funding from Lundbeck Ltd. The citation for the initial pathway is:


The Red Flags referral criteria were developed in 2014 by the UK AbbVie medical team in conjunction with UK PD clinicians in a project initiated and funded by AbbVie.

These pathways were developed by consensus working groups, membership includes:

- **Dr Neil Archibald**, Consultant neurologist, James Cook University Hospital, Middlesbrough
- **Louise Ebenezer**, Parkinson’s disease nurse specialist, Abertawe Bro Morgannwg University Health Board, South Wales
- **Professor Ray K Chaudhuri**, National Parkinson Foundation, International Centre of Excellence, King’s College London
- **Dr Robin Fackrell**, Consultant physician, Royal United Bath Hospital
- **Katherine French**, Service improvement manager, Parkinson’s UK
- **Dr Sarah Jackson**, Consultant in movement disorders and healthcare for older people, Royal Devon and Exeter NHS Trust
- **Alison Leake**, Parkinson’s disease nurse specialist, St. George’s Hospital, London
- **Jane Price**, Parkinson’s disease nurse specialist, Powys Teaching Health Board, South Wales
- **Anne Martin**, Parkinson’s disease nurse specialist, King’s College Hospital, London
- **Lucy Mooney**, Lead movement disorder nurse / Senior Parkinson’s research nurse, Southmead Hospital, Bristol
- **Charles Rendell**, Strategy manager, Care Quality Commission
- **Dr Paul Worth**, Consultant neurologist, Addenbrooke’s Hospital, Cambridge
- **Dr Alan Whone**, Consultant neurologist and senior lecturer, Southmead Hospital, Bristol

**Chair: Sue Thomas**, Chief Executive, NHiS Commissioning Excellence
Using this ICP

Overview pathway

Pathway close ups

Overview pathway

Click on the numbered circles to see a more detailed pathway describing exactly what should happen in that section.

You can also get to these detailed pathways by selecting the tab ‘Pathway close-ups’.
Ensure that the individual has information on ‘one-stop shops’ or crisis intervention services. Also, appropriate self-management information, and any other appropriate contact or services information, on discharge from hospital or other care setting.
Overview pathway

Diagnosis

Ongoing management

Multi-disciplinary management

Dementia support and care

Continuing Healthcare

Crisis intervention/support

Medicines management

Respiratory pathway

Palliative care in the community

Social care: advice and support

Voluntary sector - Parkinson's UK services & local support groups

Crisis support

Intermediate care

End of life care pathway

Specialist palliative care

End of life care discussions

Respiratory services

Dementia care pathway

Non-oral therapy

APO-go PEN

Advanced decision to refuse treatment

Advance care planning

Patient

Medicines management

Social care and support

Using this ICP

KPIs and QIs

Additional information

Governance policy

Information provision

Action planning

Accompanying documents

You can also get to these detailed pathways by selecting the tab 'Pathway close-ups'.

Provide:

- Details of direct payments, personal budgets and such, and offer to arrange an appointment to discuss these options in more detail.
- Information for relevant equipment services, such as 'one-stop shops', joint equipment stores.
- Information on available support as appropriate to circumstances including tailoring if needed for self-funders or part-funders.
- Clear information regarding eligibility criteria, self-assessments and funding assessments, and regarding the different types of funding, including that available for carers.

Click on the numbered circles to see a more detailed pathway describing exactly what should happen in that section.
Ensure full information is provided or signposted to about:

- Advanced decisions to refuse treatment;
- Advance care planning, what that might entail, and all the information required to make informed choices;
- Legal requirements such as wills and bequests, and power of attorney.
Ensure patient understands their medication regime, the implications of the medication they are taking, any lifestyle changes they need to undertake, and any key changes in condition which might indicate that a review is required. Ensure the patient is aware that their medication should be reviewed on a 6-monthly basis.
Ensure patient is directly given, or signposted to, information about the relevant local and national charities available; social care advice and support; and other relevant leisure and lifestyle information, such as the DVLA.
Overview pathway

KPI4 Parkinson’s education courses for people with Parkinson’s should be available at regular intervals.
In the patient’s diagnosis year, attendance on these will help providers meet the Parkinson’s Best Practice Tariff requirements.

Courses should be co-ordinated across the community multidisciplinary team, and one MDT member could take the lead for developing the course. Course dates should be planned in advance and shared with patients at diagnosis so they can choose when they want to attend.

**KPI:** Dates for courses across a full calendar year are available to the public. Every patient is offered details of education days and this is recorded in their patient notes. There is an increased number of new patients attending education days and this is recorded in their notes and on SystmOne. The GP and consultant are informed by letter, or, access the patient’s records directly where this is possible.

**QI:** Patients feel they are in control, that they understand the information they are getting and that they have a choice in how to respond to it. Patients understand the support available and can use it as they need to. Professionals can access information on training courses and can easily refer / signpost Parkinson’s patients to these. Professionals plan the education days in partnership with each other and across a long-term time period. This makes sure that professionals' time is used as efficiently and effectively as possible.
The referral pathway at diagnosis encourages coordinated and timely care. Following an initial appointment with the consultant (or appointment where a suspected diagnosis is given), individuals are immediately referred into the community multi-disciplinary team (MDT) clinic. This allows for a holistic understanding of the patient. It helps decide who is the most appropriate member of the MDT to act as keyworker to that person at that time.

KPI: Data shows an increased number of referrals to the MDT following diagnosis in initial consultations. Each MDT member understands the overall needs of the patients that they act as keyworker to. Education courses are offered within 6 months to maximise patient understanding (see KPI 4). Earlier intervention enables preventative care which contributes to fewer emergency admissions and GP attendances. There is a reduced overall waiting time for referrals and a reduction in cost as multiple individual appointments are avoided.

QI: Patient satisfaction, feeling in control and self-managing; professional satisfaction feeling coordinated with colleagues, and awareness of all patients.
You can also get to these detailed pathways by selecting the tab ‘Pathway close-ups’.

KPI9: Links into mental health are improved and made clearer to professionals so that individuals with Parkinson’s have appropriate levels of access when it is needed.

KPI: Mental health staff are given training in Parkinson’s to ensure that they are comfortable receiving them as patients and can provide holistic care. An agreed specialist nurse in the area will take on the position of mental health liaison, and will meet with the mental health trust on a regular basis to check on the progress of Parkinson’s patients in their care and to feed back to other professionals involved in that person’s care, as needed.

QI: Both professionals and patients alike feel that mental health support given to individuals who need it is given in a timely manner by appropriate professionals.

See ‘Additional information’. 

Click on the numbered circles to see a more detailed pathway describing exactly what should happen in that section.
An agreed link / initial point of contact into social services / adult social care (ASC) needs to be identified by ASC for health professionals to signpost individuals into so that they can access relevant social care and support, whether around independent living, respite care, equipment, or anything else. This will help health professionals to effectively support their patients to access the social care support they need without confusion, and in line with the social care system.
Overview pathway

**DIAGNOSIS**
- Patient
- Diagnosis

**MAINTENANCE AND COMPLEX**
- Medicines management
- Ongoing management
- Multi-disciplinary management
- Crisis support
- Intermediate care
- Education

**END OF LIFE**
- End of life care discussions
- Specialist palliative care
- Palliative care in the community
- End of life care pathway

**Voluntary sector - Parkinson’s UK services & local support groups**

**Social care: advice and support**

**Crisis support**

**Intermediate care**

**Non-oral therapy**
- APO-go PEN
- APO-go Pump or Duodopa

**Respiratory services**

**Dementia care pathway**

**End of life care discussions**

**Medicines management**

**Social care and support**

**KPIs and QIs**

**Governance policy**

**Information provision**

**Action plan**

**Accompanying documents**

**Click on the numbered circles to see a more detailed pathway describing exactly what should happen in that section.**

**You can also get to these detailed pathways by selecting the tab ‘Pathway close-ups’.**

**G5**

**Governance issue:** Care planning may not be uniform across an area with separate care plans used within health and social care, fragmenting services where they might be better co-ordinated.

**Possible resolution:** Prior to discharge from hospital, a member of the patient’s MDT will work with the patient and hospital to agree the patient’s discharge plan, which will incorporate health and social care. They will liaise with social care to ensure support is there for the patient on discharge.

**Longer-term aim:** All patients are offered a single care plan to span health and social care. This is either held by the patient, or stored electronically, and both health and social care staff refer to and update it.
**Intermittent apomorphine administration pathway (1)**

**Patient with Parkinson’s**

**WHEN:** Symptoms impacting on quality of life*

- **SYMPTOM CHECK LIST**
  - Unpredictable off periods
  - Early morning off
  - Delayed on
  - Dystonia
  - Difficulty in eating
  - Difficulty in opening bowels - rectal dysenergia
  - Delayed gastric emptying
  - Non-motor off
  - Motor fluctuations
  - Significant impulse control
  - Motor off severe enough to create difficulty getting to work, undertake family activities etc.

- **IS THERE OPTIMAL USE OF ORAL THERAPY?**
- **IS TABLET TIMING APPROPRIATE?**
  - Consider:
    - Concordance
    - Comorbidity issues
    - Polypharmacy
    - Constipation

**Review medication to optimise**
**Treat issues that may impact on optimising therapy**

**Initiate under the advice of a HCP who has experience of initiating APO-go/apomorphine.**

**Exclusion considerations**
- Visual impairment (unless assistance can be given by carer or nurse)
- Severe cognition issues
- Manual dexterity poor (with lack of care giver who could support)
- Significant peripheral oedema
- Caution with low BMI
- Needle phobia (caution not exclusion)

**Baseline measures**
- Postural BP (refer to guidelines)
- There is no requirement for APO-go, clinical decision-making suggests
- Baseline FBC
- Cognitive assessment
- ECG

**Optional:**
- Coombs’ test
- MOCA

**Suitable for apomorphine**

**Initiation pathway**

*NB: Apomorphine is not morphine, it is not a controlled drug and has no opioid effects or addictive properties*
**Intermittent apomorphine administration pathway (1)**

**Patient with Parkinson’s**

**WHEN:** Symptoms impacting on quality of life*

- **SYMPTOM CHECK LIST**
  - Unpredictable off periods
  - Early morning off
  - Delayed on
  - Dystonia
  - Difficulty in eating
  - Difficulty in opening bowels - rectal dysenergia
  - Delayed gastric emptying
  - Non-motor off
  - Motor fluctuations
  - Significant impulse control
  - Motor off severe enough to create difficulty getting to work, undertake family activities etc.

- **IS THERE OPTIMAL USE OF ORAL THERAPY?**

- **IS TABLET TIMING APPROPRIATE?**

  **Consider:**
  - Concordance
  - Comorbidity issues
  - Polypharmacy
  - Constipation

**YES**

- Review medication to optimise
- Treat issues that may impact on optimising therapy

**NO**

- Initiate under the advice of a HCP who has experience of initiating APO-go/apomorphine.

**Exclusion considerations**

- Visual impairment (unless assistance can be given by carer or nurse)
- Severe cognition issues
- Manual dexterity poor (with lack of care giver who could support)
- Significant peripheral oedema

**Baseline measures**

- Postural BP (refer to guidelines)
- There is no requirement for APO-go, clinical decision-making suggests
- Baseline FBC
- Cognitive assessment
- ECG

**Optional:**

- Coombs’ test
- MOCA

**Suitable for apomorphine**

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**NB:** Apomorphine is not morphine, it is not a controlled drug and has no opioid effects or addictive properties

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**Expert Consensus Group report on the use of apomorphine in the treatment of Parkinson’s disease.**

Clinical practice recommendations available online at [http://dx.doi.org/10.1016/j.parkreldis.2015.06.012](http://dx.doi.org/10.1016/j.parkreldis.2015.06.012)
**Intermittent apomorphine administration pathway (2)**

1. **Eligibility criteria met?**
   - **INITIATE INTERMITTENT APOMORPHINE**
   - Ensure patient has received education about implications of drug use and consents obtained.

2. **Pre-load domperidone 10mg TDS for 2-3 days as per MHRA Guidelines**
   - Reviewed by Movement Disorders team
   - Motor Assessment Modified UPDRS
   - Non-motor symptoms assessment (NMSQ, NMSS, PDQ8, PDSS)

3. **APOMORPHINE RESPONSE TEST**: Appropriate setting, for example: GP surgery or location authorised by Parkinson’s or movement disorder specialist.
   - Response test to be started when patient is ‘off’
   - Ensure baseline measures have been taken.

4. **UPDRS Timed walk test 20% improvement**
   - **INITIATION** linked to summary of product characteristics (SPC)
   - Discharge with initiation Trial Pack
   - Organise ongoing prescribing

5. **Further patient education + monitoring**
   - Face to face follow-up 1-3 days
   - Britannia phone service* teleclinic@britnurse.com
   - Follow up at 7 days then 1 month

6. **Ongoing review**

**OUTCOME MEASURES**
- Motor outcome
- Non-motor outcome
- Quality of life outcome
- Care giver outcome

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*If medication is withheld so patient is in an off state note patient will have to get to hospital to undergo challenge so 6am medication dose may be required.*

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**NB:** Apomorphine is not morphine, it is not a controlled drug and has no opioid effects or addictive properties.

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Click on the numbered circles to see a more detailed pathway describing exactly what should happen in that section.

You can also get to these detailed pathways by selecting the tab ‘Pathway close-ups’.
**Intermittent apomorphine administration pathway (2)**

**Patient**

**Eligibility criteria met?**

INITIATE INTERMITTENT APOMORPHINE

Ensure patient has received education about implications of drug use and consents obtained

- Non-motor symptoms assessment (NMSQ, NMSS, PDQ8, PDSS)
- Reviewed by Movement Disorders team
- Motor Assessment Modified UPDRS

APOMORPHINE RESPONSE TEST*:

- Appropriate setting, for example: GP surgery or location authorised by Parkinson’s or movement disorder specialist
- Response test to be started when patient is 'off'
- Ensure baseline measures have been taken

**APOMORPHINE RESPONSE TEST**

- POSITIVE RESPONSE?
  - UPDRS Timed walk test 20% improvement

INITIATION

- Linked to summary of product characteristics (SPC)
- Discharge with initiation Trial Pack
- Organise ongoing prescribing

**Further patient education + monitoring**

- Face to face follow-up 1–3 days
- Brittainia phone service*
- teleclinic@britnurse.com

**Follow up at 7 days then 1 month**

- Ongoing review

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*Expert Consensus Group report on the use of apomorphine in the treatment of Parkinson’s disease. Clinical practice recommendations available online at [http://dx.doi.org/10.1016/j.parkreldis.2015.06.012](http://dx.doi.org/10.1016/j.parkreldis.2015.06.012)*

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**NB:** Apomorphine is not morphine, it is not a controlled drug and has no opioid effects or addictive properties.

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**KPIs and QIs**

**Additional information**

**Governance policy**

**Information provision**

**Action plan**

**Accompanying documents**

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Click on the numbered circles to see a more detailed pathway describing exactly what should happen in that section.

You can also get to these detailed pathways by selecting the tab ‘Pathway close-ups’.
Non-oral therapy

Patient suitable for non-oral therapy

Previous dopamine agonist adverse effects including impulse control disorder, excessive daytime sleepiness

- YES
- NO

Consider apomorphine

- Apomorphine is not morphine, it is not a controlled drug and has no opioid effects or addictive properties

Consider DBS or levodopa infusion

Treatment-related adverse events

Any or all of age >70, mild dementia, falls, dysarthria, freezing of gait, severe depression?

- YES
- NO

- Treatment-related adverse events

- Favours levodopa infusion

- Favours deep brain stimulation

Adapted from Worth PF Practical Neurology 2013
Non-oral therapy

Patient suitable for non-oral therapy

Previous dopamine agonist adverse effects including impulse control disorder, excessive daytime sleepiness

Accompanying documents

Red flag criteria and qualifying statements

Referral criteria for consideration of an non-oral therapy

Primary indication:
- Poorly controlled, fluctuating symptoms which impact on quality of life
  - Disabling dyskinesias
  - Severe and frequent on/off fluctuations
  - Non-motor symptoms occurring exclusively during ‘off’ periods or which clearly worsen at the end of a dopaminergic dose (‘wearing off’)

Any of these symptoms can lead to delayed on (excess time to on after taking medication, or dose failures), GI dysfunction, functional impairment, poor mobility, falls or pain, and thus may adversely impact quality of life.

Patients with impulse control disorders whose motor complications were previously well controlled with dopaminergic therapies may also be candidates for referral. The withdrawal of dopaminergic therapies necessary for management may lead to unacceptable deterioration of motor and non-motor symptoms.

Minority indication:
1. Disabling tremor incompletely controlled by medication (indication for DBS only)
   Tremor of marked amplitude may severely interfere with daily activities. When disabling tremor is incompletely controlled by medication, including optimised doses of one or more of levodopa, dopamine agonists, trihexyphenidyl (unless contraindicated), alone or in combination, referral for DBS should be considered.

These statements were drafted and reviewed by UK clinicians as part of a project initiated and funded by the medical affairs group at AbbVie UK.
Non-oral therapy

Patient suitable for non-oral therapy

Previous dopamine agonist adverse effects including impulse control disorder, excessive daytime sleepiness

Accompanying documents

Red flag criteria and qualifying statements

Pre-requisites for consideration of an non-oral therapy

- **Diagnosis of idiopathic PD**
  There is no proven efficacy of non-oral therapies in the management of atypical parkinsonian disorders such as MSA and PSP.

- **Levodopa responsive**
  A small minority of patients with idiopathic Parkinson’s disease respond poorly to L-dopa. A documented, excellent response of motor symptoms to oral levodopa is required for referral.

- **Motivated patient**
  Patients should be aware of the more invasive nature of non-oral therapies, the required period of hospitalisation, and potential risk of complications following initiation of these treatments. Long distance travel to specialist centres may be needed for both initiation and follow-up appointments. Patients and caregivers should have realistic expectations of the benefits that can be achieved and be prepared to make an informed commitment to the therapy*.

- **Optimal trial of oral / transdermal therapy**
  An optimal trial of oral / transdermal therapy would include a trial of the following agents, alone or in combination if clinically indicated: long-acting (i.e. once daily) dopamine agonists, short-acting dopamine agonists, fractionation of L-dopa dose as well as use of monoamine oxidase B inhibitors and/or COMT inhibitors and amantadine. Failure of therapy is characterised by a lack of adequate improvement of dyskinesia or motor fluctuations; or by poor tolerability due to adverse events. Evidence like AM-IMPAKT study that suggest APO-go PEN can help to optimise oral therapy by bypassing GI system.

*APO-go can be administered in a centre close to the patient’s home. No hospital stay is required for apomorphine.
1. **Non-oral therapy**

   - **Patient suitable for non-oral therapy**
   - **Previous dopamine agonist adverse effects including impulse control disorder, excessive daytime sleepiness**
   - **YES**
   - **NO**

   - **Consider apomorphine**

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**Accompanying documents**

**Red flag criteria and qualifying statements**

**Contraindications for consideration of an non-oral therapy**

- **Severe dementia**
  Irrespective of motor symptoms, marked cognitive impairment may render a patient unable to function independently, and understand and cooperate with the non-oral therapies. In some situations, the presence of behavioural symptoms may risk actual harm to the patient e.g. pulling out PEG tube.

- **Chronic psychosis unresponsive to medication adjustment**
  Active psychosis should be treated, and be stabilised, prior to consideration of non-oral therapies. Some psychotic phenomena (i.e. visual hallucinations, delusional beliefs) can be caused or exacerbated by dopaminergic medications. Patients whose psychotic symptoms persist, despite adjustment of their dopaminergic medication and/or addition of atypical neuroleptics/cholinesterase inhibitors, are unsuitable for any non-oral therapy.

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2 Non-oral therapy: continuous apomorphine (from intermittent PEN)

- **Patient**
  - Currently on apomorphine PEN
  - Define motor fluctuations

- **Non-motor symptoms assessment** (NMSQ, NMSS, PDQ8, PDSS)
- **Reviewed by Movement Disorders team**
- **Motor Assessment Modified UPDRS**
- **Consider addition to intermittent therapy**
  - CONVERT TO PUMP
    - **HAS MEDICATION BEEN OPTIMISED?**
      - **YES**
        - Infusion
      - **NO**
        - Review

- **Consider delivery option of apomorphine**
  1) Pump, 2) Pen and pump or 3) Consensus of international KOLs suggests 6 or more injections/day should be considered for PUMP

- **EMERGENCY LINK**
  - PDNS or APO-go nurse consulting with Movement disorders specialist, will assess patient at home and initiate therapy

- **Follow-up and ongoing support to be**
  - PDNS APO-go nurse
  - Training of DN, Residential & nursing staff and qualified staff

- **Consultant follow-up within 1 month**

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**KPIs and QIs**

**Additional information**

**Governance policy**

**Information provision**

**Action plan**

**Accompanying documents**
**Non-oral therapy: continuous apomorphine (from intermittent PEN)**

- **Patient**: Currently on apomorphine PEN

  - Define motor fluctuations

  - Non-motor symptoms assessment (NMSQ, NMSS, PDQ8, PDSS)

  - Reviewed by Movement Disorders team

  - Motor Assessment Modified UPDRS

- **HAS MEDICATION BEEN OPTIMISED?**

  - **YES**
    - Infusion
  
  - **NO**
    - Review

- **Consider addition to intermittent therapy**

  - **CONVERT TO PUMP**

    - **EMERGENCY LINK**

      1. Pump
      2. Pen and pump
      3. Consensus of international KOLs suggests 6 or more injections/day should be considered for PUMP

    - **Criteria for INITIATION**

      1. Has medication been optimised?
      2. As per previous eligibility from intermittent pathway

    - Ongoing education

      - Patient
      - Carer
      - District nurses and others

    - Review existing medication whilst titrating pump

    - PDNS or APO-go nurse consulting with Movement disorders specialist, will assess patient at home and initiate therapy

    - Baseline measures

      - Baseline FBC
      - ECG
      - Cognitive assessment
      - Postural BP (refer to guidelines)

      - Optional:

        - Coombs’ test
        - MOCA

- **Follow-up and ongoing**

  - PDNS

  - Training of DN, Residential & Support Staff

**KPIs and QIs**

**Additional information**

**Governance policy**

**Information provision**

**Action planning**

**Accompanying documents**

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**i9**


Clinical practice recommendations available online at [http://dx.doi.org/10.1016/j.parkreldis.2015.06.012](http://dx.doi.org/10.1016/j.parkreldis.2015.06.012)
Non-oral therapy: continuous apomorphine (from intermittent PEN)

1. Patient Currently on apomorphine PEN
   - Define motor fluctuations
   - Evidence of increased use of intermittent injection
   - Unpredictable fluctuations

2. HAS MEDICATION BEEN OPTIMISED?
   - Yes: Infusion
   - No: Review

3. Consider delivery option of apomorphine
   - 1) Pump, 2) Pen and pump or 3) Consensus of international KOLs suggests 6 or more injections/day should be considered for PUMP

4. EMERGENCY LINK
   - PDNS or APO-go nurse with Movement disorders specialist will assess patient at home and initiate therapy

5. Consider addition to intermittent therapy
   - Convert to PUMP
   - Criteria for INITIATION
     - As per previous eligibility from intermittent pathway

6. Baseline measures
   - Baseline FBC
   - ECG
   - Cognitive assessment
   - Postural BP (refer to guidelines)

   Optional:
   - Coombs’ test
   - MOCA

7. Non-motor symptoms assessment (NMSQ, NMSS, PDQ8, PDSS)
   - Reviewed by Movement Disorders team
   - Motor Assessment Modified UPDRS

8. EMERGENCY / CONTINGENCY PLANS
   - Pump failure - 24 hour HELPLINE (technical): 0844 880 1327
   - Breakdown of established route e.g. 111 cases
   - Emergency supply of medical + equipment
   - Inpatient guidelines for product information
   - Best oral / patch therapy alternative

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KPIs and QIs
Additional information
Governance policy
Information provision
Action plan
Accompanying documents
**Advanced therapy: Patient new to apomorphine, considered for continuous infusion**

**Patient with Parkinson’s**

**WHEN:** Symptoms impacting on quality of life*

**REASONS TO CONSIDER APOMORPHINE**
- Unpredictable off periods
- Early morning off
- Delayed on
- Dystonia
- Difficulty in eating
- Difficulty in opening bowels
- Rectal dysenesthesia
- Delayed gastric emptying
- Non-motor off
- Motor fluctuations
- Significant impulse control
- Motor off severe enough to cause pain

**IS THERE OPTIMAL USE OF ORAL THERAPY?**

**IS TABLET TIMING APPROPRIATE?**

**Consider:**
- Concordance
- Comorbidity issues
- Polypharmacy
- Constipation

**Review medication to optimise**

**Treat issues that may impact on optimising therapy**

**Initiate under the advice of a HCP who has experience of initiating APO-go/apomorphine.**

**Suitable for apomorphine**

**Initiation pathway**

**EXCLUSION CONSIDERATIONS**
- Needle phobia (caution not exclusion)
- Blind (unless has suitable support from formal or informal carers)
- Severe cognition issues
- Manual dexterity poor (with lack of care giver who could support)
- Significant peripheral oedema
- Caution with low BMI

**OTHER CONSIDERATIONS FOR DISCUSSION / CLARIFICATION**
- Consideration of carers / significant others / supporters
- Travel letters / protocol for travel
- Sharps disposal
- Home delivery options
2a) **Advanced therapy: Patient new to apomorphine, considered for continuous infusion**

**Patient with Parkinson’s**

**WHEN:** Symptoms impacting on quality of life*

**REASONS TO CONSIDER APOMORPHINE**
- Unpredictable off periods
- Early morning off
- Delayed on
- Dystonia
- Difficulty in eating
- Difficulty in opening bowels - rectal dysenergia
- Delayed gastric emptying
- Non-motor off
- Motor fluctuations
- Significant impulse control
- Motor off severe enough to cause pain

**IS THERE OPTIMAL USE OF ORAL THERAPY?**

**IS TABLET TIMING APPROPRIATE?**
- Consider:
  - Concordance
  - Comorbidity issues
  - Polypharmacy
  - Constipation

**EXCLUSION CONSIDERATIONS**
- Needle phobia (caution not exclusion)
- Blind (unless has suitable support from formal or informal carers)
- Severe cognition issues
- Manual dexterity poor (with lack of care giver who could support)
- Significant peripheral oedema
- Caution with low BMI

**Review medication to optimise**
- Treat issues that may impact on optimising therapy

**Initiate under the advice of a HCP who has experience of initiating APO-go/apomorphine.**

**Suitable for apomorphine**

**Initiation pathway**

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**KPIs and QIs**

**Additional information**

**Governance policy**

**Information provision**

**Action planning**

**Accompanying documents**

---

**Expert Consensus Group report on the use of apomorphine in the treatment of Parkinson’s disease.**

Clinical practice recommendations available online at [http://dx.doi.org/10.1016/j.parkreldis.2015.06.012](http://dx.doi.org/10.1016/j.parkreldis.2015.06.012)
Advanced therapy: Initiation pathway for continuous apomorphine

1. Patient
2. Eligibility criteria met?
   INITIATE INTERMITTENT APOMORPHINE
3. Pre-load domperidone 10mg TDS for 2-3 days as per MHRA Guidelines
4. APOMORPHINE RESPONSE TEST*
   Appropriate setting with old medication after pre-load domperidone
5. Response test to be started when patient is 'off'
   Ensure baseline measures have been taken
6. POSITIVE RESPONSE?
   UPDRS Timed walk test 20% improvement
7. INITIATION
   linked to summary of product characteristics (SPC)
8. Discharge with initiation Trial Pack
9. Organise ongoing prescribing
10. Ongoing review

REASONS FOR DISCONTINUATION OF PUMP

Further patient education + monitoring
1. Face to face follow-up 1-3 days
   Britannia phone service *
2. Follow up at 7 days then 1 month

OUTCOME MEASURES
- Motor outcome
- Non-motor outcome
- Quality of life outcome
- Care giver outcome

Additional information
Governance policy
Information provision
Action plan
Accompanying documents
KPIs and QIs
Non-oral therapy
Non-oral therapy: Continuous apo (intermittent PEN)
Advanced apomorphine - New patient
Initiation pathway continuous apomorphine
Deep brain stimulation...
2b Advanced therapy: Initiation pathway for continuous apomorphine

- Patient
  - Eligibility criteria met?
    - Initiate intermittent apomorphine
  - Pre-load domperidone 10mg TDS for 2-3 days as per MHRA Guidelines
  - APOMORPHINE RESPONSE TEST: Appropriate setting with old medication after pre-load domperidone

- Non-motor symptoms assessment (NMSQ, NMSS, PDQ8, PDSS)
- Reviewed by Movement Disorders team
- Motor Assessment Modified UPDRS

- Positive response?
  - UPDRS Timed walk test 20% improvement

- Initiation
  - Linked to summary of product characteristics (SPC)
  - Discharge with initiation Trial Pack
  - Organise ongoing prescribing

- Further patient education + monitoring
  - Face to face follow-up 1-3 days
  - Britannia phone service
  - Follow up at 7 days then 1 month

- Ongoing review

Additional information
  - Clinical practice recommendations available online at http://dx.doi.org/10.1016/j.parkreldis.2015.06.012
**Advanced therapy: Initiation pathway for continuous apomorphine**

1. **Patient**
2. **Eligibility criteria met?**
   - **INITIATE INTERMITTENT APOMORPHINE**
   - Ensure patient has received education about implications of drug use and consents obtained

3. **Pre-load domperidone 10mg TDS for 2-3 days as per MHRA Guidelines**
4. **APOMORPHINE RESPONSE TEST**:
   - Appropriate setting with old medication after pre-load domperidone
   - Ensure baseline measures have been taken
5. **Response test to be started when patient is 'off'**
6. **POSITIVE RESPONSE?**
   - **UPDRS Timed walk test 20% improvement**
   - **INITIATION**
     - LINKED TO SUMMARY OF PRODUCT CHARACTERISTICS (SPC)

---

**REASONS FOR DISCONTINUATION OF PUMP**

- Severe nodules
- Postural hypotension
- Patient choice
- Need for alternative therapy e.g. Duodopa or DBS
- Worsening cognitive issues
- Psychosis leading to delusions
- Emaciated frail patient

---

**KPIs and QIs**

**Additional information**

**Governance policy**

**Information provision**

**Action plan**

**Accompanying documents**
Deep Brain Stimulation (DBS) pathway

1. Non-oral therapy
2. Advanced apomorphine - New patient
3. Initiation pathway continuous apomorphine
4. Deep brain stimulation
5. Duodopa – Referral
6. Duodopa – Specialist
7. Duodopa – Review

- **Patient**
  - GP
  - Movement disorders specialist
  - Neuroscience centre

- **Specialised functional neurosurgery unit / Consultant neurosurgeon / Consultant neurologist**
  - MDT assessment including neurophysiological assessment, neuro-imaging, lab investigations
  - DBS suitability and eligibility determined
  - Elective DBS surgery scheduled / DBS procedure conducted
  - Post-op assessment
  - Multi-disciplinary team
  - Satellite DBS clinic

- **Ongoing management**
  - Patient unsuitable for DBS
  - Follow-ups should be regular, and adjustments should be made as needed to the device and medication.
  - Where available, follow-ups at local satellite clinics should take place, with liaison with the local MDT.

- **DBS is a specialised service commissioned by the NHS Commissioning Board (not CCGs)**
- **Referrals to adult neurosurgery specialist centres are accepted from primary, secondary and tertiary care.**

---

**KPIs and QIs**

**Additional information**

**Governance policy**

**Information provision**

**Action plan**

**Accompanying documents**
3 Deep Brain Stimulation (DBS) pathway

Non-oral therapy

Advanced apomorphine - New patient

Initiation pathway continuous apomorphine

Deep brain stimulation

Duodopa - Referral

Duodopa - Specialist

Duodopa - Review

Patient

GP

Movement disorders specialist

Neuroscience centre

Specialised functional neurosurgery unit / Consultant neurosurgeon / Consultant neurologist

MDT assessment including neurophysiological assessment, neuro-imaging, lab investigations

DBS suitability and eligibility determined

Elective DBS surgery scheduled/ DBS procedure conducted

Ongoing management

Patient unsuitable for DBS

DBS is a specialised service commissioned by the NHS Commissioning Board (not CCGs)

Referrals to adult neurosurgery specialist centres are accepted from primary, secondary and tertiary care.

Further information on DBS recommendations, and the clinical and cost-effectiveness of DBS in Parkinson's disease is available to download in an app search “earlystimulus” in Apple and Android or at https://www.earlystimulus.com/
Deep Brain Stimulation (DBS) pathway

1. Non-oral therapy
2. Non-oral therapy: Continuous apo (intermittent PEN)
2a. Advanced apomorphine - New patient
2b. Initiation pathway continuous apomorphine
3. Deep brain stimulation
3a. Duodopa - Referral
3b. Duodopa - Specialist
3c. Duodopa - Review

Patient

GP

Movement disorders specialist

Neuroscience centre

Specialised functional neurosurgery unit / Consultant neurosurgeon / Consultant neurologist

Ongoing management

MDT assessment including neurophysiological assessment, neuro-imaging, lab investigations

Patient unsuitable for DBS

DBS suitability and eligibility determined

Multi-disciplinary team

Elective DBS surgery scheduled/DBS procedure conducted

Post-op assessment

Follow ups should be regular, and adjustments should be made as needed to the device and medication.

DBS is part of specialised services that are commissioned using a nationally consistent approach, meaning that patients will have equal access to high quality services, regardless of where they live.

http://www.england.nhs.uk/2013/04/04/clinical-access-policies/
Deep Brain Stimulation (DBS) pathway

1. Non-oral therapy
2. Non-oral therapy: Continuous apo (intermittent PEN)
   2a. Advanced apomorphine - New patient
2b. Initiation pathway continuous apomorphine
3. Deep brain stimulation
   3a. Duodopa - Referral
   3b. Duodopa - Specialist
   3c. Duodopa - Review

- **Patient**
  - GP
  - Movement disorders specialist
  - Neuroscience centre

- **Specialised functional neurosurgery unit / Consultant neurosurgeon / Consultant neurologist**

- **Ongoing management**
  - MDT assessment including neurophysiological assessment, neuro-imaging, lab investigations
  - DBS suitability and eligibility determined
  - Multi-disciplinary team

- **Deep Brain Stimulation (DBS) procedure conducted**
  - Elective DBS surgery scheduled
  - Post-op assessment

- **Follow ups** should be regular, and adjustments should be made as needed to the device and medication.

- Referrals to adult neurosurgery specialist centres are accepted from primary, secondary and tertiary care.

DBS is a specialised service commissioned by the NHS Commissioning Board (not CCGs)

Additional information
- Governance policy
- Information provision
- Action plan
- Accompanying documents

Make sure patients are given, or signposted to, a copy of Parkinson's UK’s ‘Surgery for Parkinson's’, available in ‘Accompanying documents’ as both a link, and an embedded pdf.
3 Deep Brain Stimulation (DBS) pathway

Non-oral therapy

- Continuous apomorphine

Initiation pathway

- New patient

Deep brain stimulation

- Referral

- Specialist

- Review

Ongoing management

- Patient unsuitable for DBS

Specialised functional neurosurgery unit / Consultant neurosurgeon / Consultant neurologist

- MDT assessment including neurophysiological assessment, neuro-imaging, lab investigations

- DBS suitability and eligibility determined

Elective DBS surgery scheduled / DBS procedure conducted

Governance policy:

Specialised neurosurgery units must meet standards outlined in the NHS Commissioning Board service specification for Adult Neurosurgery.


Functional neurosurgery units specialising in DBS must additionally fulfil the standards set out in the National Toolkit for the Designation of DBS Providers (September 2011).
3a Duodopa – Referral for specialist unit opinion on patient suitability

**Patient**

WHEN:
- Fluctuations in condition
- Biologically old/young
- SEE Referral tips

**REASONS NOT TO REFER:**
- Patients who have not tried or been found unsuitable for apomorphine
- Moderate dementia
- Not responsive to levodopa

**REASONS TO REFER:**
- Inclusion criteria include unsuitable or unable to tolerate apomorphine
- Patient has suitable symptoms
- Patient is responsive to levodopa

**YES**
- Patient identified as being suitable for Duodopa
- Baseline Weights and Vitamin B12 levels
- Request specialist opinion

**OPINION NOT SUITABLE**
- Feedback to referrer
- Identify centres where Duodopa is provided
- Appropriate symptoms + Good drug history + Good home care support

**Eligible for Duodopa**

**Specialist Pathway**

**OUTCOME MEASURES**
- Motor outcome
- Non-motor outcome
- Quality of life outcome
- Care giver outcome
3b Duodopa – Specialist

- Eligibility criteria met
  - Oral therapy compromised
  - OTHER NON-ORAL THERAPIES
    - Test if suitable for apomorphine
    - Test if suitable for DBS

- Non-motor symptoms assessment (NMSQ, NMSS, PDQ8, PDSS)

- Reviewed by Movement Disorders team

- Motor Assessment

- Inpatient for levodopa challenge (optional)
  - NG tube optional

- Intrajejunal levodopa Infusion (IJLI)

- Refer to Gastroenterology Duodopa team

- Monitoring

- Referral to specialist neuroscience centre

- To Duodopa, apomorphine or DBS pathway depending on clinical decision

Non-oral therapy matrix

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G10 Governance policy:
Specialised neuroscience units must meet the standards outlined in the NHS England service specification for Adult Neurosciences


http://www.england.nhs.uk/2015/07/02/annual-investment-decisions/
3b Duodopa – Specialist

Accompanying document:

Specialist centres initiating Duodopa 2016:

Greater London
King’s College Hospital
National Hospital for Neurology & Neurosurgery
Bart’s & The London Centre for Neurosciences Royal London Hospital
Charing Cross Hospital
St George’s Hospital

East Midlands
Queen’s Medical Centre, Nottingham

West Midlands
Queen Elizabeth Hospital, Birmingham
University Hospital Coventry & Warwickshire

North West
Walton Centre, Liverpool
Salford Royal NHS Foundation Trust
Royal Preston Hospital

East England
Queen’s Hospital, Romford
Alderbrook’s Hospital, Cambridge

Yorkshire & The Humber
Leeds General Infirmary
John Radcliffe Hospital, Oxford

North East England
Royal Victoria Infirmary, Newcastle
James Cook University Hospital, Middlesbrough

South East England
Southampton General Hospital

South West
Southmead Hospital Bristol

Scotland
Guidance is in place in Scotland for the prescribing of duodopa from 13th June 2016. Any Trust can have duodopa on its formulary and therefore have a service. Currently (October 2016) Southern General Hospital, Glasgow is providing a service.

Wales and Northern Ireland
In 2016 for any patient who requires duodopa in Wales and Northern Ireland a business case is compiled for individual funding. A movement disorders specialist screens patients (application only) before funding is agreed with each area. Currently funding is through Individual Funding Requests IPFR in Wales; IFR in NI.

https://www.scottishmedicines.org.uk/SMC_Advice/Advice/316_06_co_careldopa_Duodopa/co_careldopa_levodopa_Duodopa_2nd_Resubmission
**3c Duodopa – Review**

- **Patient**
  - Eligible for Duodopa
  - Commenced on treatment

- **Specialist Pathway**

- **BASELINE MEASURES:**
  - Bloods
  - EMG
  - Vitamin B12 levels
  - Weight

- **FOLLOW UP**
  - One week
  - One month
  - Three months
  - Six months

- **Outcome Measures**
  - Motor outcome
  - Non-motor outcome
  - Quality of life outcome
  - Care giver outcome

- **Emergency**
  - Tube issues
    - Emergency Supply of oral medication
    - Agreed by local team
    - 24 hour help line
    - Diet
  - Psychological Support

- **In first instance contact Specialist Centre**

- **Information for Carers**
  - Independence advice/risk advice
  - Travel protocol

- **Link with Intelligence Network**

- **Duodopa – Review**

**Non-oral therapy**

**Non-oral therapy: Continuous apo (intermittent PEN)**

**Advanced apomorphine - New patient**

**Initiation pathway continuous apomorphine**

**Deep brain stimulation**

**Duodopa – Referral**

**Duodopa – Specialist**

**Duodopa – Review**
### Quality Indicators and KPIs

#### KPI 4

**Parkinson's education courses for people with Parkinson's should be available at regular intervals.**

In the patient's diagnosis year attendance on these will help providers meet the Parkinson's Best Practice Tariff requirements.

Courses should be co-ordinated across the community multidisciplinary team and one MDT member could take the lead for developing the course. Course dates should be planned in advance and shared with patients at diagnosis so they can choose when they want to attend.

**KPI:** Dates for courses across a full calendar year are available to the public. Every patient is offered details of education days and this is recorded in their patient notes. There is an increased number of new patients attending education days and this is recorded in their notes and on SystmOne. The GP and consultant are informed by letter, or, access the patient’s records directly where this is possible.

**QI:** Patients feel they are in control, that they understand the information they are getting and that they have a choice in how to respond to it. Patients understand the support available and can use it as they need to. Professionals can access information on training courses and can easily refer / signpost Parkinson's patients to these. Professionals plan the education days in partnership with each other and across a long-term time period. This makes sure that professionals' time is used as efficiently and effectively as possible.

#### KPI 6

**The referral pathway at diagnosis encourages coordinated and timely care.** Following an initial appointment with the consultant (or appointment where a suspected diagnosis is given), individuals are immediately referred into the community multi-disciplinary team (MDT) clinic. This allows for a holistic understanding of the patient. It helps decide who is the most appropriate member of the MDT to act as keyworker to that person at that time.

**KPI:** Data shows an increased number of referrals to the MDT following diagnosis in initial consultations. Each MDT member understands the overall needs of the patients that they act as keyworker to. Education courses are offered within 6 months to maximise patient understanding (see KPI 4). Earlier intervention enables preventative care which contributes to fewer emergency admissions and GP attendances. There is a reduced overall waiting time for referrals and a reduction in cost as multiple individual appointments are avoided.

**QI:** Patient satisfaction, feeling in control and self-managing; professional satisfaction feeling coordinated with colleagues, and awareness of all patients.
### Quality Indicators and KPIs

| KPI 9 | Links into mental health are improved and made clearer to professionals so that individuals with Parkinson's have appropriate levels of access when it is needed.  
KPI: Mental health staff are given training in Parkinson’s to ensure that they are comfortable receiving them as patients and can provide holistic care. An agreed specialist nurse in the area will take on the position of mental health liaison, and will meet with the mental health trust on a regular basis to check on the progress of Parkinson’s patients in their care and to feed back to other professionals involved in that person’s care, as needed.  
QI: Both professionals and patients alike feel that mental health support given to individuals who need it is given in a timely manner by appropriate professionals. |
|---|---|
| KPI 11 | Where an individual with Parkinson’s is admitted to hospital, or has a hospital outpatient appointment, the coding reflects that they have Parkinson’s regardless of whether or not the condition was the main reason for their admission. Their condition should also be coded regardless of which hospital department they are seen in, or are under the care of.  
KPI: Hospital Episode Statistics (HES) data begins to reflect working practice more closely. Numbers of admissions may appear to increase initially because they are being accurately coded. This might highlight potential changes in working practice to consider. |

A26
## Additional information

| A6   | End of life care discussions can be introduced by any member of the community MDTs, specialist neurology nurses, palliative care team or MFE team able to make a home visit and with training in end of life care discussions. Timing of advanced discussions should be tailored to the individual according to their needs. For example, someone exhibiting early cognitive impairment or communication challenges might need to have these discussions at an earlier point whilst they are still able to clearly make their wishes known.  
**Commissioning recommendation:** Commission end of life training for all those providing home visits and those in residential care settings so that they are equipped to have these discussions. Examples of End of Life training days provided elsewhere by NCS are available on request. |
| A18  | An agreed link / initial point of contact into social services / adult social care (ASC) needs to be identified by ASC for health professionals to signpost individuals into so that they can access relevant social care and support, whether around independent living, respite care, equipment, or anything else. This will help health professionals to effectively support their patients to access the social care support they need without confusion, and in line with the social care system. |
| A26  | There is concern that individuals with Parkinson’s who need a more specialist level of mental health support are not always accepted into mental health services. In addition to making links across neurology and mental health clearer, as this pathway recommends, training for mental health staff in the essentials of Parkinson’s is recommended so that they feel comfortable and able to provide holistic treatment.  
**Commissioning recommendation:** Consider some form of training or education for mental health staff in what it means to live with Parkinson’s disease, and the links with mental health. |
| A27  | Further information on DBS recommendations, and the clinical and cost-effectiveness of DBS in Parkinson’s disease is available to download in an app search “earlystimulus” in Apple and Android or at https://www.earlystimulus.com/  
‘Accompanying documents’ |
| A28  | DBS is part of specialised service that are commissioned using a nationally consistent approach, meaning that patients will have equal access to high quality services, regardless of where they live.  
http://www.england.nhs.uk/2013/04/04/clinical-access-policies/ |
### Governance policies and issues

<table>
<thead>
<tr>
<th>G5</th>
<th>Governance issue:</th>
<th>Care planning may not be uniform across an area with separate care plans used within health and social care fragmenting services where they might be better coordinated.</th>
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<tbody>
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<td>Possible resolution:</td>
<td>Prior to discharge from hospital, a member of the patient’s MDT will work with the patient and hospital to agree the patient’s discharge plan, which will incorporate health and social care. They will liaise with social care to ensure support is there for the patient on discharge.</td>
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<td>Longer-term aim:</td>
<td>All patients are offered a single care plan to span health and social care. This is either held by the patient, or stored electronically, and both health and social care staff refer to and update it.</td>
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<tr>
<th>G8</th>
<th>Governance policy:</th>
<th>Specialised neurosurgery units must meet standards outlined in the NHS Commissioning Board service specification for Adult Neurosurgery.</th>
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<td><a href="http://www.england.nhs.uk/2015/07/02/annual-investment-decisions/">http://www.england.nhs.uk/2015/07/02/annual-investment-decisions/</a></td>
</tr>
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## Information provision: standardised / suggested

### i3
Ensure that the individual has information on 'one-stop shops' or crisis intervention services. Also, appropriate self-management information, and any other appropriate contact or services information, on discharge from hospital or other care setting.

### i4
Provide:
- details of direct payments, personal budgets and such, and offer to arrange an appointment to discuss these options in more detail.
- information for relevant equipment services, such as 'one-stop shops', joint equipment stores.
- information on available support as appropriate to circumstances including tailoring if needed for self-funders or part-funders.
- clear information regarding eligibility criteria, self-assessments and funding assessments, and regarding the different types of funding, including that available for carers.

### i5
Ensure full information is provided or signposted to around:
- Advanced decisions to refuse treatment;
- Advance care planning, what that might entail, and all the information required to make informed choices;
- Legal requirements such as wills and bequests, and power of attorney.

### i6
Ensure patient understands their medication regime, the implications of the medication they are taking, any lifestyle changes they need to undertake, and any key changes in condition which might indicate that a review is required. Ensure the patient is aware that their medication should be reviewed on a 6-monthly basis.

### i7
Ensure patient is directly given, or signposted to, information about the relevant local and national charities available; social care advice and support; and other relevant leisure and lifestyle information, such as the DVLA.

### i8
Make sure patients are given, or signposted to, a copy of Parkinson's UK's 'Surgery for Parkinson's', available in 'Accompanying documents' as both a link, and an embedded pdf.

### i9
Expert Consensus Group report on the use of apomorphine in the treatment of Parkinson's disease. Clinical practice recommendations available online at [http://dx.doi.org/10.1016/j.parkreldis.2015.06.012](http://dx.doi.org/10.1016/j.parkreldis.2015.06.012).
### Action plan - what needs doing, when, by who

Identify actions that need to be carried out to make sure the pathway works as well as possible. This table is left blank for you to populate.

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<th>Core workstream</th>
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## Action plan - what needs doing, when, by who (continued)

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Overview pathway
Diagnosis
Ongoing management
Multi-disciplinary management
Dementia support and care
Continuing Healthcare Care
Crisis intervention/support
Medicines management
Respiratory pathway
Palliative care in the community
Social care management
Deep Brain Stimulation pathway
End of life care pathway

KPIs and QIs
Additional information
Governance policy
Information provision
Action plan
Accompanying documents

Accompanying documents

Useful links
- Continuing healthcare checklist
- NICE Guidance for Parkinson's
- The National Service Framework for Long Term Conditions
- End of life Neurology Strategy
- The Gold Standard Framework and associated toolkit
- Parkinson's UK
- Parkinson's Info Sheet

Hello,
If you have just been diagnosed, or know somebody who has, you've probably got lots of questions, and perhaps some worries. That's where Parkinson's UK comes in. Parkinson's UK is the biggest Parkinson's support and research charity. We're committed to finding a cure and improving life for everyone affected by Parkinson's. We provide a range of information and support, including expert staff and nurses, a free confidential helpline, our website and 330 local groups. Please get in touch if you need more information.

Our helpline
Our expert nurses and helpline staff are here to provide impartial information about all aspects of Parkinson's, including taking medication, claiming benefits and much more. And you can contact them if you just need to contact someone about living with the condition. Anyone affected by Parkinson's can call or email the helpline for support and information. The service is confidential and calls are free from land lines and most mobile networks. An interpreting service is available for anyone who doesn't speak English.

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Our website
Our website is packed with information about Parkinson's. Join our online discussion forum to share your experiences of living with Parkinson's and chat to other people in the same situation. Visit parkinsons.org.uk or drop us a line at hello@parkinsons.org.uk. You can also order our free information resources, DVDs and audio tapes on our website, at parkinsons.org.uk/publications or by emailing parkinsons@sharward.co.uk, or call 01473 212 115.
Accompanying documents

Other useful documents

- Parkinson’s Best Practice Tariff
- Medicines Management Standard
- Information on Deep brain stimulation
- PD Surg UK clinical trial info & publications available from study website
- Parkinson’s UK ‘Surgery for Parkinson’s (click on icon)
- Memory Matters FAIR Decision Tree
- Non-motor symptoms questionnaire
Accompanying documents

Memory Matters FAIR (Find, Assess, Investigate, Refer) Decision Tree

1. **Q:** Has the person been more forgetful in the last 12 months to the extent that it has significantly affected their daily life?
   - **NO**
   - **YES**

2. **Diagnostic assessment**
   - **Positive** (scores < 8)
   - **Inconclusive**
   - **Negative** (scores ≥ 8+)

3. **Specialist Referral**

- **Feedback to GP**

- **Usual care**

Additional information

Patients for whom the case finding question cannot be completed within 72 hours for reason of coma, critical illness, severe speech or language difficulties, sensory impairment, lack of translator, family or professional care giver. Readmissions and frequent attenders without a diagnosis of dementia will be excluded if there is evidence of these patients having been assessed within the last 6 months.
**Accompanying documents**

**Specialist centres initiating Duodopa 2016**

**Greater London**
King’s College Hospital  
National Hospital for Neurology & Neurosurgery  
Bart’s & the London Centre for Neurosciences Royal London Hospital  
Charing Cross Hospital  
St George’s Hospital

**East Midlands**
Queen’s Medical Centre, Nottingham

**West Midlands**
Queen Elizabeth Hospital, Birmingham  
University Hospital Coventry & Warwickshire

**North West**
Walton Centre, Liverpool  
Salford Royal NHS Foundation Trust  
Royal Preston Hospital

**Yorkshire & The Humber**
Leeds General Infirmary  
John Radcliffe Hospital, Oxford

**North East England**
Royal Victoria Infirmary, Newcastle  
James Cook University Hospital, Middlesbrough

**South East England**
Southampton General Hospital

**South West**
Southmead Hospital Bristol

**Scotland**
Guidance is in place in Scotland for the prescribing of duodopa from 13th June 2016. Any Trust can have duodopa on its formulary and therefore have a service. Currently (October 2016) Southern General Hospital, Glasgow is providing a service.  
https://www.scottishmedicines.org.uk/SMC_Advice/Advice/316_06_co_careldopa_Duodopa/co_careldopa_levodopa_Duodopa_2nd_Resubmission  
https://www.scottishmedicines.org.uk/About_SMC/Latest_news/News_Articles/June_2016_decisions_news_release

**Wales and Northern Ireland**
In 2016 for any patient who requires duodopa in Wales and Northern Ireland a business case is compiled for individual funding. A movement disorders specialist screens patients (application only) before funding is agreed with each area. Currently funding is through Individual Funding Requests (IPFR in Wales; IFR in NI).
Accompanying documents

Red flag criteria and qualifying statements

**Referral criteria for consideration of an non-oral therapy**

**Primary indication:**

- **Poorly controlled, fluctuating symptoms which impact on quality of life**
  - Disabling dyskinesias
  - Severe and frequent on/off fluctuations
  - Non-motor symptoms occurring exclusively during ‘off’ periods or which clearly worsen at the end of a dopaminergic dose (‘wearing off’)

Any of these symptoms can lead to delayed on (excess time to on after taking medication, or dose failures), GI dysfunction, functional impairment, poor mobility, falls or pain, and thus may adversely impact quality of life.

Patients with impulse control disorders whose motor complications were previously well controlled with dopaminergic therapies may also be candidates for referral. The withdrawal of dopaminergic therapies necessary for management may lead to unacceptable deterioration of motor and non-motor symptoms.

**Minority indication:**

1. **Disabling tremor incompletely controlled by medication (indication for DBS only)**
   
   Tremor of marked amplitude may severely interfere with daily activities. When disabling tremor is incompletely controlled by medication, including optimised doses of one or more of levodopa, dopamine agonists, trihexyphenidyl (unless contraindicated), alone or in combination, referral for DBS should be considered.

These statements were drafted and reviewed by UK clinicians as part of a project initiated and funded by the medical affairs group at AbbVie UK.
Red flag criteria and qualifying statements (continued)

Pre-requisites for consideration of an non-oral therapy

- **Diagnosis of idiopathic PD**
  There is no proven efficacy of non-oral therapies in the management of atypical parkinsonian disorders such as MSA and PSP.

- **Levodopa responsive**
  A small minority of patients with idiopathic Parkinson's disease respond poorly to L-dopa. A documented, excellent response of motor symptoms to oral levodopa is required for referral.

- **Motivated patient**
  Patients should be aware of the more invasive nature of non-oral therapies, the required period of hospitalisation, and potential risk of complications following initiation of these treatments. Long distance travel to specialist centres may be needed for both initiation and follow-up appointments. Patients and caregivers should have realistic expectations of the benefits that can be achieved and be prepared to make an informed commitment to the therapy*

- **Optimal trial of oral / transdermal therapy**
  An optimal trial of oral / transdermal therapy would include a trial of the following agents, alone or in combination if clinically indicated: long-acting (i.e. once daily) dopamine agonists, short-acting dopamine agonists, fractionation of L-dopa dose as well as use of monoamine oxidase B inhibitors and/or COMT inhibitors and amantadine. Failure of therapy is characterised by a lack of adequate improvement of dyskinesia or motor fluctuations; or by poor tolerability due to adverse events. Evidence like AM-IMPACT study that suggest APO-go PEN can help to optimise oral therapy by bypassing GI system.

*APO-go can be administered in a centre close to the patients home. No hospital stay is required for Apomorphine.
### Contraindications for consideration of an non-oral therapy

<table>
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<th><strong>Severe dementia</strong></th>
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<td>Irrespective of motor symptoms, marked cognitive impairment may render a patient unable to function independently, and understand and cooperate with the non-oral therapies. In some situations, the presence of behavioural symptoms may risk actual harm to the patient e.g. pulling out PEG tube.</td>
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<th><strong>Chronic psychosis unresponsive to medication adjustment</strong></th>
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<td>Active psychosis should be treated, and be stabilised, prior to consideration of non-oral therapies. Some psychotic phenomena (i.e. visual hallucinations, delusional beliefs) can be caused or exacerbated by dopaminergic medications. Patients whose psychotic symptoms persist, despite adjustment of their dopaminergic medication and/or addition of atypical neuroleptics/cholinesterase inhibitors, are unsuitable for any non-oral therapy.</td>
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Text relay 18001 0808 800 0303 (for textphone users only)
Email hello@parkinsons.org.uk

Our Parkinsons Local Advisors

Our Parkinsons Local Advisors can provide confidential one-to-one information, support and signposting. They can also visit you at home if necessary.

Get in touch with your Parkinsons Local Advisor

Call our helpline on 0808 800 0303 or email hello@parkinsons.org.uk for local contact details.

Our website

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You can also order our free information resources, DVDs and audio tapes on our website, at parkinsons.org.uk/publications or by emailing resources@parkinsons.org.uk or call 0845 121 2354