# MONEY AND PARKINSON'S





# YOUR MONEY & PARKINSON'S

This 4-week financial planning programme is designed for individuals with Parkinson's disease (PD) and their families to navigate the financial challenges that can come with managing a chronic condition.

This UK-specific financial planning guide is tailored to the progressive stages of Parkinson's disease, providing key actions at each stage to ensure that you and your family are financially prepared for future needs.

## THIS PROGRAMME



#### **LEARN**

Each week we focus on an aspect of financial planning



#### **ACTION**

We then ask you to try making changes and tracking your progress



#### **REVIEW**

At the end of each week we would like you to review your progress.



#### Stage 1: Early (Mild Symptoms, Minimal Impact on Daily Life)

#### **Financial Tasks:**

#### **Build an Emergency Fund:**

 Aim to save 3-6 months' worth of living expenses to cover unexpected health or financial emergencies.

#### **Create a Detailed Budget:**

- Track all sources of income (including salary, pensions, or other benefits).
- Include current Parkinson's-related medical costs, such as prescription charges, travel for appointments, or therapies.

#### **Review Health and Disability Benefits:**

- Ensure you're aware of what support is available via the NHS for Parkinson's treatments.
- Investigate Personal Independence Payment (PIP) to assist with daily living and mobility costs if your condition starts affecting you early on. Even if your symptoms are mild, it's worth understanding the eligibility criteria.

#### **Assess Critical Illness or Income Protection Insurance:**

 If still employed, review any critical illness insurance or income protection insurance policies you may have. These can provide a payout or income if you're unable to work due to Parkinson's.

#### **Consider Long-Term Care Planning:**

- Explore options for long-term care insurance to cover future care needs.
- Consider funding arrangements like equity release as a way to access the value of your home if long-term care becomes necessary.

#### Set Up Lasting Power of Attorney (LPA):

- It's crucial to create an LPA for Property and Financial Affairs to appoint someone you trust to manage your financial matters if you become unable to do so.
- You may also want to set up an LPA for Health and Welfare to ensure your medical and care preferences are respected

#### **Begin Estate Planning:**

- Ensure you have a will that reflects your current wishes and outlines how your assets will be distributed.
- o Consider setting up a trust if you want to protect assets for specific beneficiaries.

# Stage 2: Moderate (Increased Symptoms, Some Impact on Daily Life)

#### **Financial Tasks:**

#### **Reassess Your Budget:**

- Adjust your budget to account for increased medical costs (e.g., more frequent treatments or therapies).
- Cut back on discretionary spending if necessary to manage growing health-related expenses.

#### Apply for PIP (If Not Already Done):

If your condition is worsening, you may now be eligible for Personal Independence
 Payment (PIP) or an increase in the award amount if you are already receiving it.

#### **Explore Employment Support:**

- If working becomes difficult, consider applying for Statutory Sick Pay (SSP) or Employment and Support Allowance (ESA).
- Check if your employer offers any workplace adjustments under the Equality Act 2010, such as flexible hours or changes in duties.

#### **Maximise Benefits:**

- If you or your partner are over 66, ensure you're claiming the State Pension and any related benefits such as Attendance Allowance.
- · Check eligibility for Carer's Allowance if a family member is providing significant care.

#### **Consult a Financial Adviser:**

Seek advice on protecting your savings and investments as your health needs evolve. A
financial adviser can help with retirement planning or adjusting your investments for longterm care.

#### **Plan for Long-Term Care:**

- Start researching costs for in-home care, residential care, or care homes. The cost of longterm care in the UK varies greatly by location, so get a sense of the fees and funding options.
- Explore local authority support and self-funding arrangements if care becomes a necessity. Contact your local council for a needs assessment.

#### **Plan for Home Modifications:**

 Consider budgeting for or applying for grants (e.g., Disabled Facilities Grant) to cover the cost of home adaptations, such as installing handrails or stairlifts, to accommodate your changing mobility.

# Stage 3: Advanced (Significant Impact on Daily Life, Increased Dependence)

#### **Financial Tasks:**

#### **Maximise PIP and Attendance Allowance:**

 Ensure you're receiving the highest level of PIP if you need daily assistance or mobility support. If over 66, you may qualify for Attendance Allowance instead, which helps with personal care costs.

#### **Consider Carer's Benefits:**

• If a family member is taking on caregiving duties, they may qualify for Carer's Allowance, providing additional financial support.

#### **Activate Lasting Power of Attorney (LPA):**

- If your condition significantly impairs your ability to manage financial affairs, your appointed LPA should take over management of your accounts, investments, and day-to-day finances.
- The LPA for Health and Welfare can also be activated to make healthcare decisions on your behalf.

#### **Review Long-Term Care Funding:**

- If you need residential or nursing home care, check your eligibility for NHS
   Continuing Healthcare (CHC) funding. This is fully funded care for those with significant healthcare needs and can cover care home costs.
- Speak to your local authority about means-tested support for care home fees if you're self-funding.

#### **Consider Care Home Planning:**

- Research the costs and availability of local care homes. These vary across the UK, so check for facilities in your area and compare their fees, services, and CQC ratings.
- Make sure your estate plan is updated to reflect any changes in financial circumstances due to long-term care costs.

#### **Review State Benefits and Council Support:**

 Apply for all relevant local authority financial assessments to ensure you're not missing out on means-tested benefits, including council tax reductions for those with disabilities.

#### **Stage 4: Late (Severe Symptoms, Total Dependence)**

#### **Financial Tasks:**

#### **Ensure Long-Term Care is Covered:**

 Confirm that any care home costs are covered either through NHS Continuing Healthcare, local authority support, or your savings. Review whether deferred payment schemes (via your local authority) are an option if you own property but wish to avoid selling it to pay for care.

#### **Use Carer Support Services:**

 If care is provided by family members at home, look into additional services provided by the NHS or local councils for respite care or financial assistance through Carer's Allowance.

#### **Prepare for End-of-Life Care:**

 Review palliative care options with your healthcare provider and ensure that any end-oflife care is fully funded by NHS Continuing Healthcare or the local authority.

#### **Ensure Will and Trusts Are Up to Date:**

- Review your will and ensure that all your wishes regarding the distribution of your assets are documented clearly.
- If applicable, ensure any trusts (e.g., a disabled person's trust) are properly funded and managed to provide financial security for your beneficiaries.

#### **Plan for Funeral Expenses:**

Consider setting aside funds or a pre-paid funeral plan to cover funeral and burial costs.
 This relieves the financial burden on family members at a difficult time.

#### **Organise Financial Documents:**

• Ensure all financial documents (e.g., bank accounts, pensions, investment portfolios, and property deeds) are well-organised and accessible to the executor of your estate.

# Here's a list of UK-specific references and resources that can be helpful for financial planning related to Parkinson's disease:

#### **Government and Legal Resources**

#### **Citizens Advice Bureau (CAB):**

- Provides free advice on benefits, debt, and legal matters related to illness and disability.
- [https://www.citizensadvice.org.uk](https://www.citizensadvice.org.uk)

#### **Gov.uk Benefits and Financial Support for Disability:**

· Provides information on benefits such as Personal Independence Payment (PIP),

#### Attendance Allowance, and \*\*Employment and Support Allowance (ESA).

[https://www.gov.uk/financial-help-disabled](https://www.gov.uk/financial-help-disabled)

#### Disability Living Allowance (DLA) for children with disabilities under 16.

[https://www.gov.uk/disability-living-allowance-children](https://www.gov.uk/disability-living-allowance-children)

### The MoneyHelper (formerly The Money Advice Service)Offers free advice and tools on budgeting, benefits, and financial management.

[https://www.moneyhelper.org.uk](https://www.moneyhelper.org.uk

### Power of Attorney (UK Government Guidance) Information on setting up a \*\*Lasting Power of Attorney (LPA) to manage finances and healthcare decisions.

• [https://www.gov.uk/power-of-attorney](https://www.gov.uk/power-of-attorney)

#### **Health and Care Resources**

#### **NHS Continuing Healthcare**

Funding provided by the NHS for long-term health conditions, which could help with care home or in-home care costs for advanced Parkinson's.

[https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare/](https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare/)

#### **NHS Personal Health Budgets**

A scheme where individuals can manage their own NHS care and support budget to meet their personal healthcare needs.

[https://www.nhs.uk/using-the-nhs/help-with-health-costs/what-is-a-personal-health-budget/] (https://www.nhs.uk/using-the-nhs/help-with-health-costs/what-is-a-personal-health-budget/)

#### **Care Quality Commission (CQC)**

For reviewing and finding regulated care homes or services for long-term care planning. [https://www.cqc.org.uk]

#### **Parkinson's Disease Support**

#### Parkinson's UK

Offers financial guidance, support, and resources specific to Parkinson's. They provide information on benefits, work, and care options for individuals with Parkinson's in the UK. [https://www.parkinsons.org.uk]

#### Turn2Us

A national charity helping people in financial hardship. Offers an online benefits calculator and grants search tool.

[https://www.turn2us.org.uk](https://www.turn2us.org.uk)

#### **Tax and Financial Planning**

HM Revenue & Customs (HMRC) - Disability-Related Tax Relief:

Provides information on tax relief and benefits for individuals with disabilities, including VAT exemptions\*\* and tax credits for disability-related expenses.

[https://www.gov.uk/financial-help-disabled/vat-relief](https://www.gov.uk/financial-help-disabled/vat-relief)

#### The Pension Service (DWP)

Helps you manage pensions, including disability benefits for retirees with long-term conditions like Parkinson's.

[https://www.gov.uk/contact-pension-service](https://www.gov.uk/contact-pension-service)

#### **Age UK - Financial and Legal Planning**

Offers advice on \*\*estate planning, wills, funeral planning, and dealing with financial challenges due to illness or ageing.

[https://www.ageuk.org.uk/information-advice/money-legal/]

(https://www.ageuk.org.uk/information-advice/money-legal/)

#### **Long-Term Care and Estate Planning**

#### **Care Home Fees - UK Care Guide**

Provides insights into paying for care homes and managing long-term care costs in the UK. [https://ukcareguide.co.uk/care-home-fees/] (https://ukcareguide.co.uk/care-home-fees/)

#### Solicitors for the Elderly (SFE)

A UK membership body offering legal services and advice for older people and those with disabilities. They specialise in estate planning, lasting powers of attorney, and care funding.

- [https://sfe.legal](https://sfe.legal)

#### **StepChange Debt Charity**

- Offers free debt advice and support, especially if you're managing large healthcare expenses and struggling financially. - [https://www.stepchange.org](https://www.stepchange.org)

### 4 week programme

Take a look at the stage you are in and each week try to achieve the goals below. If you have time move onto the next stage.

#### **Early Stage:**

- · Build an emergency fund.
- · Create a budget.
- · Apply for PIP if symptoms affect daily living.
- Establish Lasting Power of Attorney (LPA) for financial and health matters.
- · Begin estate planning with a will and trust.

#### **Moderate Stage:**

- · Reassess budget for increased care costs.
- Apply for PIP or ESA if work is affected.
- Plan for long-term care costs with local authority assessments and NHS funding.
- Look into Disabled Facilities Grants for home modifications.

#### **Advanced Stage:**

- Ensure you receive full PIP or Attendance Allowance benefits.
- · Review NHS Continuing Healthcare eligibility for full care home funding.
- · Activate LPA if needed.
- · Explore Carer's Allowance for family caregivers.

#### Late Stage:

- Confirm end-of-life care is fully funded through the NHS or local authority.
- Update your will and trust as circumstances change.
- Set aside funds for funeral expenses or consider a pre-paid funeral plan.

### **GOAL TRACKER**

MAIN GOAL ACTION STEPS 1. 1. 2. 3. GOAL 3 GOAL 2 ACTION STEPS ACTION STEPS 1. 1. 2. 2. 3. **5** . 6. 7. GOAL 4 GOAL 5 ACTION STEPS ACTION STEPS 1. 1. 2. 3. 3. 4. 5. 5. 6. 6. 7. 7.