# An Introduction to Parkinson's Alasta

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We are Parkinson's UK. Powered by people Funded by you. Improving life for everyone affected by Parkinson's.

**Together we'll find a cure** 

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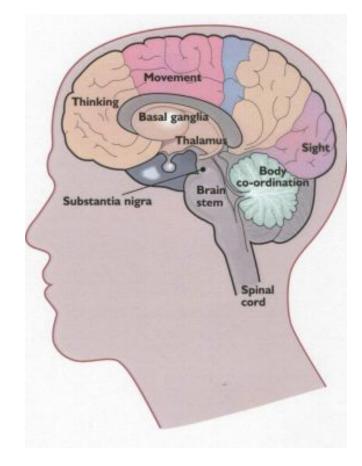
## What is Parkinson's?

- A neurological condition for which there is no cure.
- A fluctuating condition which is progressive (gets worse over time).
- Condition which affects movement, as well as a range of non-movement symptoms.
- Caused by the of lack of dopamine in the brain.
- First identified by Dr James Parkinson in 1817.

## What causes Parkinson's?

- Parkinson's occurs when dopamine producing cells are lost from the part of the brain that controls movement.
- The cause is **unknown**.
- There's currently **no cure**.
- Only 5% have a clearly inherited form of Parkinson's.
- Everyone is different.

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## Who does it affect?

- Currently around 145,000 people in the UK have Parkinson's.
- Due to an ageing population we expect this figure to grow by 18% by 2025 to 171, 000 people
- Every hour, two more people are diagnosed with Parkinson's
- Most people will be between **50-69** when diagnosed.
- Younger people get Parkinson's too but it's rarer.
- Occurs in all ethnic groups.
- Affects more men than women.

## **Causes of Parkinson's**

- We don't yet know exactly why people get Parkinson's
- Research suggest it's a combination of age, genetic and environmental factors that cause the dopamine-producing nerve cells to die
- A very small number of Parkinson's cases are **hereditary** and researchers are looking into why this happens.

## Signs and symptoms of Parkinson's

- Slowness of movement
- Poverty of movement (hypokinesia); this includes difficulty starting a movement, reduced size of movements and lack of coordination of movements
- Rigidity
- Resting tremor
- Range of other non-movement symptoms



## What are the other symptoms?



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## Some Impacts of Parkinson's on Daily Life

- Washing body and hair
- Dressing
- Preparing and cooking food
- Climbing stairs
- Speaking in person and on the phone
- Paying for purchases
- Frequent and urgent need to use the toilet
- Writing or typing (keyboard, touch screen etc)

## **Communication and Parkinson's**

- Speech can be quieter and can be slurred
- Voice may sound monotonous and lack emotion
- Ability to smile may be lost
- May have a blank facial expression
- Conversations can be tiring
- People with Parkinson's can take a longer time to respond
- Writing is very hard for some, and often writing can be small
- Typing, using a mouse of touchpad can be very difficult, and for some people impossible

## **Treatment of Parkinson's**

The symptoms can be controlled using the following combination:

Medication

- •Therapies speech and language, occupational, physiotherapist
- Occasionally surgery
- Exercise



## **Challenges of medication**

- Fluctuations in response (on/off effect)
- Wearing off
- Hallucinations, nightmares and confusion
- Impulsive and compulsive behaviour (ICB's)
- Involuntary Movements
- Timing of medication



# Parkinson's UK



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## Parkinson's UK

- Research We influence and fund groundbreaking research to advance the understanding of Parkinson's and improve treatments
- Information & Support We provide expert information and advice to support people to live well with Parkinson's
- Support for People We offer support and opportunities to 'live life to the full', for people living with Parkinson's as well as their carers and families
- Campaigning & Service Improvement- We raise awareness, change perceptions, and work in partnership to drive better services for people affected by Parkinson's

"I'm not on my own any more – I've got people who understand, people who care. Thanks to them, I've done things I would never have dreamed. Team Parkinson's is my family."

Diane Dowsett Team Parkinson's member

# TEAM PARKINSON'S

Get your pin badge



### is the movement to transform life with Parkinson's.



We care because Parkinson's affects hundreds of thousands of people in the UK. Your mum, son, partner or best friend – anyone can get Parkinson's.



# **Supporting People**

We support people with Parkinson's, their families and carers via:

- Our website www.parkinsons.org.uk
- Information and advice on how to live well with Parkinson's
- Network of local groups and activities
- Free confidential helpline 0808 800 303 including support about medication, benefits and legal right. Interpreter services for non-english speakers.
- Accessible formats large print, audio and other languages



# UK PARKINSON'S Excellence Network

The UK Parkinson's Excellence Network brings together health and social care professionals to transform care for people affected by Parkinson's.



UK Parkinson's Audit

Local Parkinson's Excellence Network groups



Excellence Network working groups



Excellence Network Conference and Awards



#### Parkinson's nurses

This pathway provides easy identification and access to relevant learning which has been mapped to the 2017 Parkinson's nurse competencies and stratified NHS bands.

Start pathway >



Occupational therapists, physiotherapists and speech and language therapists

This pathway provides information about training resources and professional development opportunities for therapists.

Start pathway >



#### Health and care staff

This pathway identifies and provides easy access to relevant learning by experience level for pharmacy staff, care staff, doctors (all), nurses, HCAs, psychiatrists, psychologists, social workers, social care assessors, dietitians and all other health and care staff.

Start pathway >

#### Popular links to information and resources

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Need information for your patients?

Giving a new diagnosis of Parkinson's?

Do you have a ward patient with Parkinson's?

Do you care for someone with Parkinson's in a care home or in their own home?



#### **Clinical tools and assessments**

All of the clinical tools and assessments in the resource directory are listed here for easy access

See the resources >



#### Guidelines for professionals

All of the professional guidelines in the resources directory are listed here for easy access.

See the resources >



South East Local Parkinson's E...

Name

South East Local Parkinson's Excellence Network

#### Local lead

Iain Wilkinson and Clare Addison

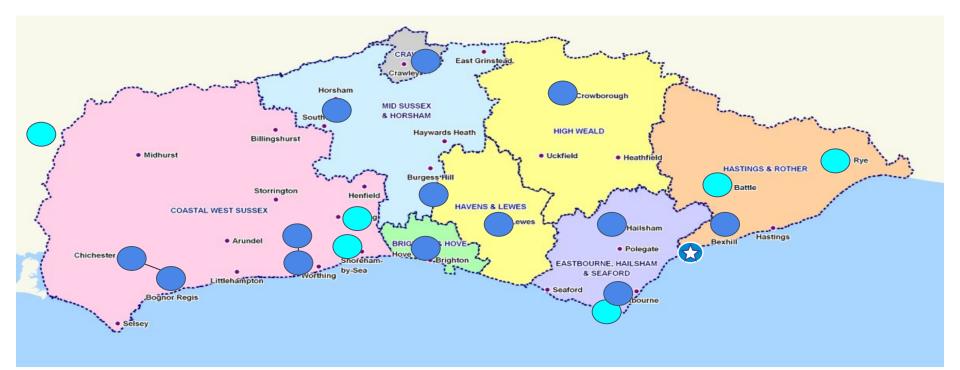
#### Find out more

www.parkinsons.org.uk/professionals/so uth-east-local-parkinsons-excellencenetwork

## **Parkinson's in Sussex**

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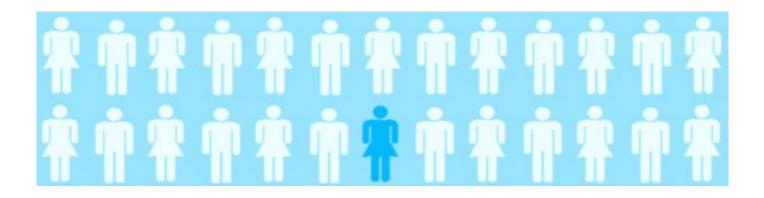
## **Sussex groups**





## Sussex

- 11 local Parkinson's UK groups
- 5 Parkinson's Cafes
- approximately 4000 people with Parkinson's (2324 West Sussex 1692 E Sussex)
- approx. 500 people over 45 diagnosed each year



## **Sussex Priorities 2021-22**

### **Priority One**

People should have better access to exercise and physical activity

### **Priority Two**

We need to reach more people who are newly diagnosed

### **Priority Three**

People at all stages of the condition should be better connected to the right support and opportunities

### **Priority Four**

People should be able to access health care professionals and require better care in hospital

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# PARKINSON'S CAN'T HOLD US BACK

## **Any Questions?**