How can we improve the journey to diagnosis and beyond?

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‘Talking lines’: Please try and think back to when you first noticed something was wrong. Please draw a line that describes your journey from that point to when you were diagnosed.

"It was like an explosion, not an immediate explosion but over a period of maybe a year or so where all of this was happening that I couldn't understand..."

"That’s what those little lines represent it’s all the little things that came together to make this big thing...the build-up"

"...then as the journey progressed with the assessments and everything, I started to get a little bit of understanding..."

"...and then the huge relief...I found it a huge relief when I got the diagnosis"

[Participant with a diagnosis of PCA]

Slide courtesy of Charlie Harrison, Creative Consultant, RDS
Awareness of atypical symptoms – early referral

Referrals accepted nationally from primary, secondary and tertiary care

Referral information for healthcare professionals

📞 020 3448 3171
📞 020 3448 3011
✉ uclh.cognitivedisordersclinic@nhs.net

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Other referral information

National referral centre for familial young onset and unusual dementias

Multidisciplinary clinic with specialist nurse, psychology, neurology and psychiatry input

www.uclh.nhs.uk/our-services/find-service/neurology-and-neurosurgery/cognitive-disorders-clinic
Maximising the clinic appointment

- Referrals triaged by consultant
- Previous investigations requested and reviewed
- Cognitive questionnaire sent out before appointment
- Clinic preparation and allocation of patients into same day MRI and neuropsychology slots

- Clinic appointment (1 hr)
  - detailed history, cognitive and neurological examination (NB. Motor features including asymmetrical upper limb rigidity seen in 30% PCA patients in our cohort. Overlap with corticobasal syndrome (CBS), due to AD

Consensus classification of posterior cortical atrophy

Sebastian J. Crutch, Jonathan M. Schott, Gil D. Rabinovici, Melissa Murray.
Investigations to support diagnostic specificity

- International diagnostic guidelines including NICE recommend imaging to rule out “reversible causes” of cognitive decline and to assist “subtype diagnosis”
- MRI preferred modality - excellent tissue contrast, lack of ionizing radiation, superior in detecting atrophy patterns, vascular burden and signal change. Susceptibility-weighted imaging sequences for microbleeds
- BUT normal MRI doesn’t exclude neurodegeneration

White matter hyperintensities and microbleeds in PSEN1 - familial AD with behavioural/dysexecutive presentation

Preserved hippocampal volume (arrowhead) & parieto-occipital atrophy (arrows) in PCA

CSF biomarkers for dementia

- Nurse-led LP clinic on daycare unit
- Positive predictive value of low abeta 42/40 ratio for diagnosis of AD higher in younger people

“Preparing for disease modifying therapies for dementia: implications for research, trials and clinical services”

NEJM November 2022, FDA licensing Jan 2023
Discussing the diagnosis and what we can do

- Explanation, time for questions, emphasis on variability in progression strategies for managing symptoms, focusing on strengths
- If AD or DLB, symptomatic therapy (cholinesterase inhibitor)
- Specialist referrals eg. ophthalmology (for registration as partially sighted in PCA) speech and language therapy in PPA (primary progressive aphasia)
- Practical considerations and sources of support locally and through RDS – further explored with specialist nurse either after clinic or in separate telephone appointment

- Research opportunities
  eg. BRAPID study – using advances in MRI physics to decrease MRI time from 20-30 to 5-7 mins, plus blood biomarkers
www.ucl.ac.uk/drc/research/clinical-trials

Our clinical trial unit is at National Hospital for Neurology and Neurosurgery, UCLH, Queen Square, London WC1N 3BG

Getting involved…

If you are interested in participating in our clinical trials or other research, please email our recruitment team at drctrialenquiries@ucl.ac.uk

The DRC also actively supports Join Dementia Research, which matches participants to appropriate research studies throughout the UK.
Injections of hope: supporting participants in clinical trials

Understanding hope and better appreciating the personal investments of trial participants could improve patient experience and trial design, argue Emma Harding, Catherine Mummery, and colleagues

Emma Harding, 1 Philip Robinson, 2 James Wilson, 3 Sebastian J Crutch, 1 Catherine J Mummery 4.1

BMJ 2021;375:e066851

Inspired by chance: valuing patients’ informal contributions to research

Serendipitous contributions from patients that influence the research agenda should be better recognised and acknowledged, argue Sebastian Crutch and colleagues

Sebastian Crutch, 1 Daniel Herron, 2 James Pickett, 3 Simon Rosser, 4 Martin Rossor 1,2

BMJ 2020;371:m4478

Contributions of patient and citizen researchers to 'Am I the right way up?' study of balance in posterior cortical atrophy and typical Alzheimer's disease

Sebastian J Crutch 1, Keir Xx Yong 3, Amy Peters 2, Dilek Ocal 3, Diego Kaski 2, Aida Suarez Gonzalez 3, Natalie Ryan 3, Simon Ball 4, Charlie R Harrison 5, Charlie Murphy 6, Pam Hulme 6, Isabel Phillips 6, Gaynor Hulme 6, Andrew Brown 6, Lu Brown 6, Peter Riley 7, Lynn Ramsey 7, Anthony Woods 8, Brian Day 9

Affiliations + expand
PMID: 30373456 DOI: 10.1177/1471301218789296

Created Out of Mind: Shaping Perceptions of Dementia Through Art and Science

Sebastian J. Crutch, Charles R. Harrison, Emile V. Brotherhood, Paul M. Camici, Brian Day & Anthony J. Woods

Chapter | First Online: 16 November 2019
579 Accesses
Part of the Springer Series on Bio- and Neurosystems book series (SSBN,volume10)
Thank you!

Colleagues, collaborators referring clinicians

All the individuals who participate in and shape research, through the questions they ask, the contributions they make and the stories they share

www.raredementiasupport/stories

www.futurelearn.com/courses/faces-of-dementia