

Primary Progressive Aphasia: State of the art

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Acknowledgements

Study participants

All the NHS trusts

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South London and Maudsley 
NHS Foundation Trust




**National Institute for
Health Research**



DEMENTIA

Alzheimer's disease

Frontotemporal dementia

Lewy body dementia

Vascular dementia

Typical Alzheimer's disease

Behavioural variant Frontotemporal dementia

Dementia with Lewy bodies

Mixed dementia

>100 others

Secondary Progressive Aphasia - Iv PPA like

Parkinson's disease dementia

Subcortical dementia

Secondary Progressive Aphasia – receptive and expressive impairments

Posterior cortical atrophy

Nonfluent PPA

Secondary Progressive Aphasia – nfvPPA like

Logopenic PPA

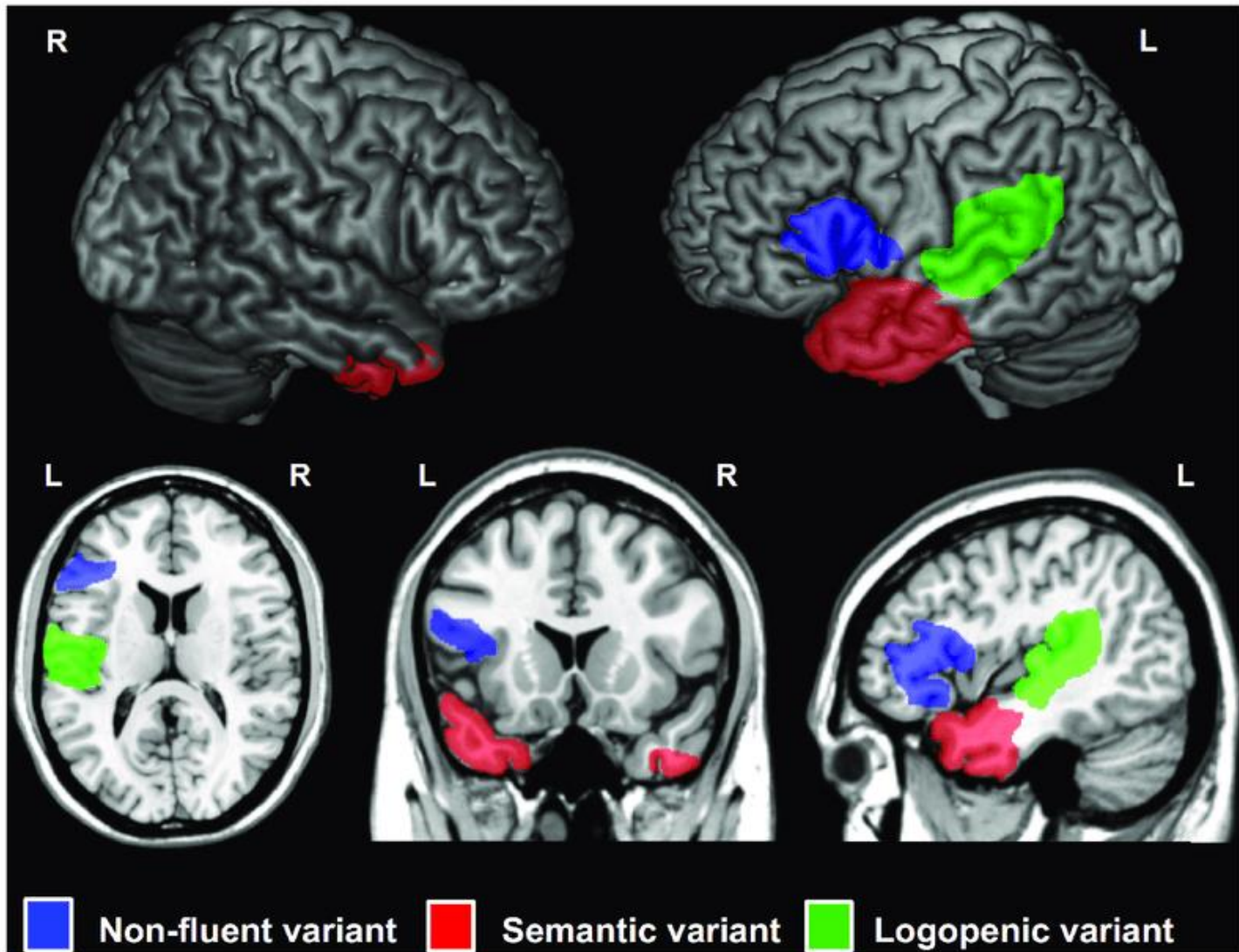
Primary Progressive Aphasia

Primary Progressive Aphasia

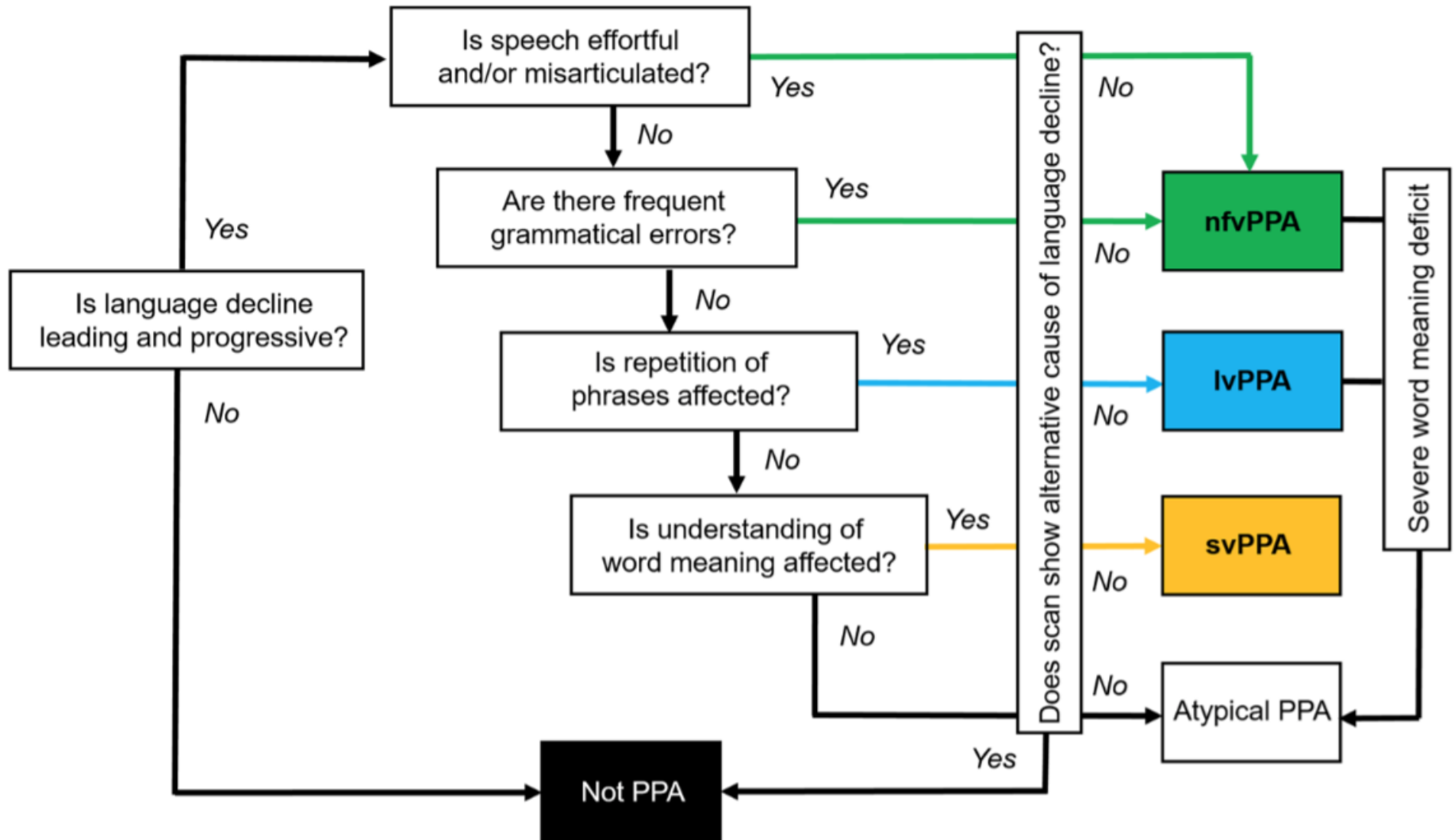
Semantic PPA	Nonfluent PPA	Logopenic PPA
Impaired confrontation naming Impaired single word comprehension + Impaired object knowledge Surface dyslexia/dysgraphia	Effortful, halting speech with inconsistent speech sound errors and distortions (apraxia) Agrammatism of expressive language + Difficulties in comprehension of syntactically complex sentences	Impaired single word retrieval in spontaneous speech Impaired repetition of sentences and phrases + Speech errors (phonological) in speech production

Semantic
 Impaired
 naming
 Impaired
 compreh

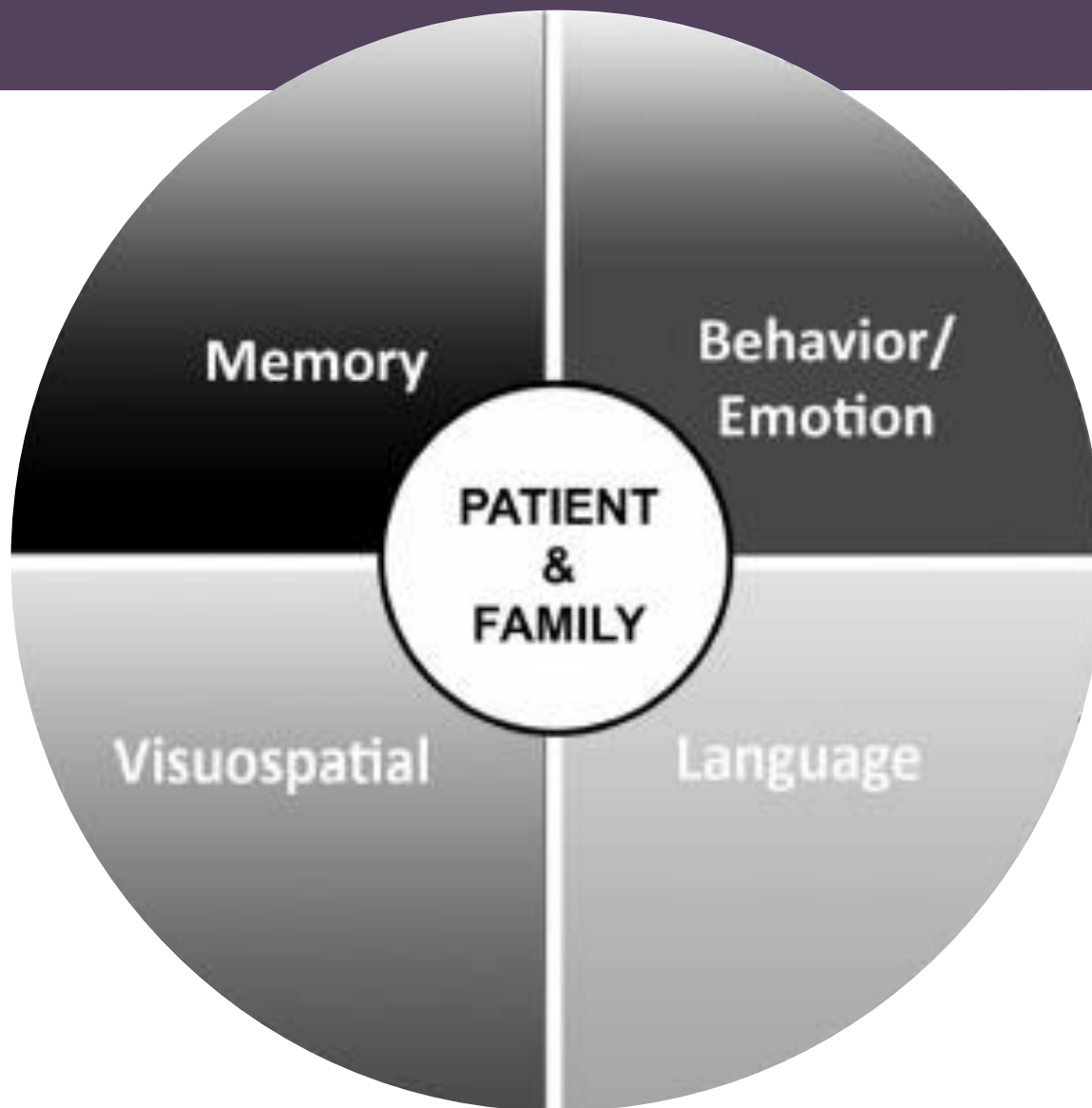
 Plus
 Impaired
 knowled
 Surface
 dyslexia



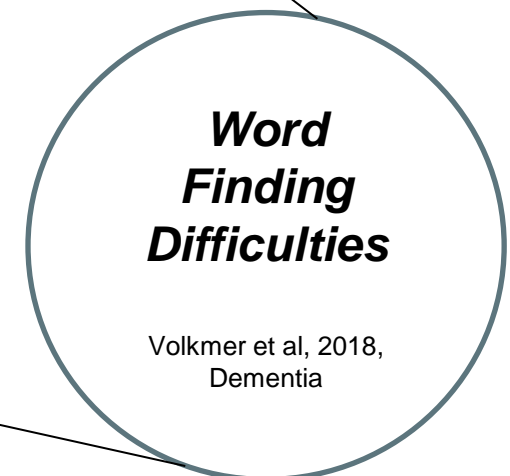
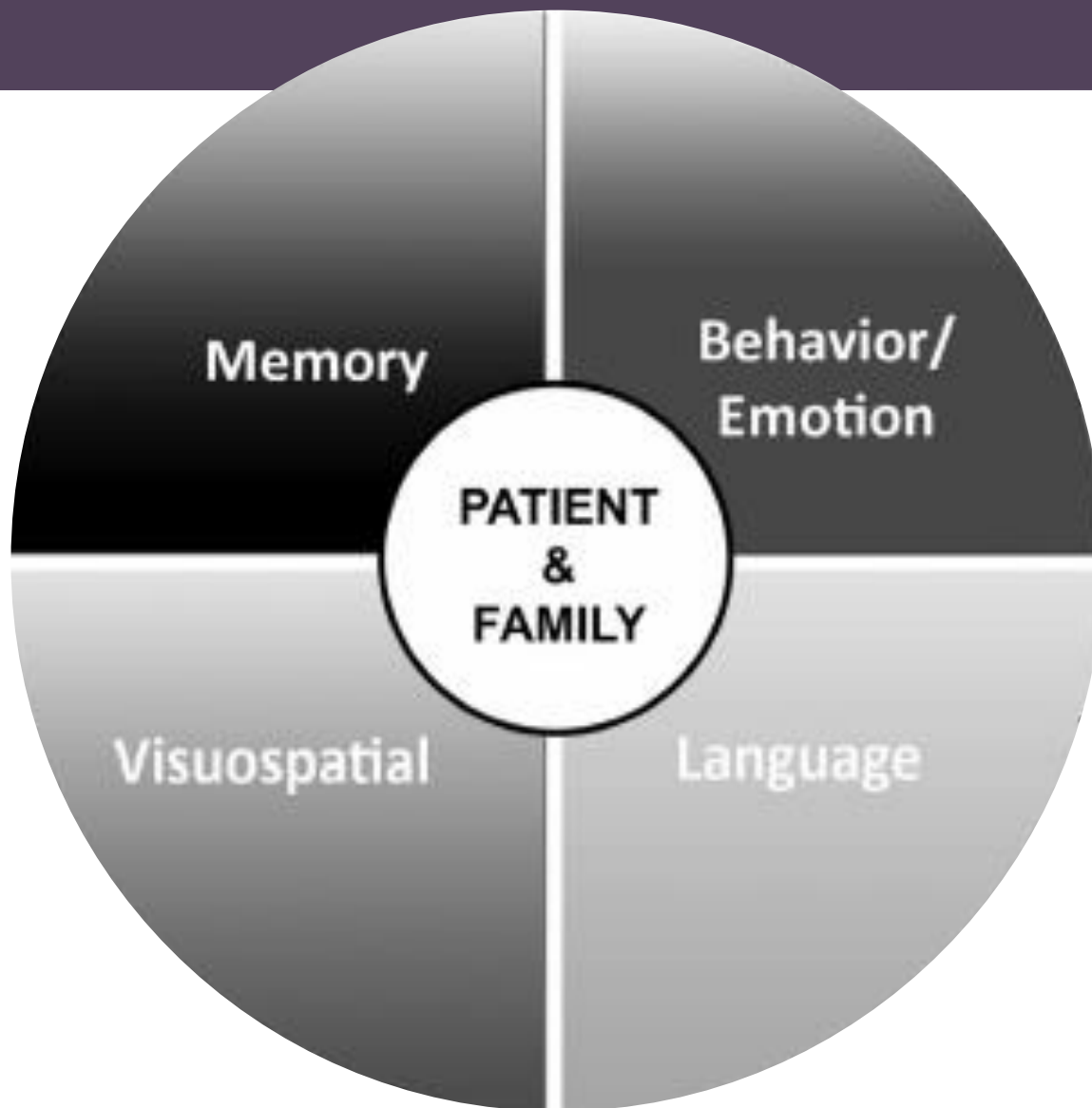
Sanches et al, 2021, Frontiers in Aging Neuroscience



Symptom led



Symptom led



Staged



Person Centered

I just want to be able to keep doing my job

What can I do to help my wife?

I love reading to my grandchildren

I really enjoy going to the pub, and I want to be able to keep doing

Other people don't understand, what can we do?

I'm so lonely and frustrated.

Best practice principles when working with people with PPA

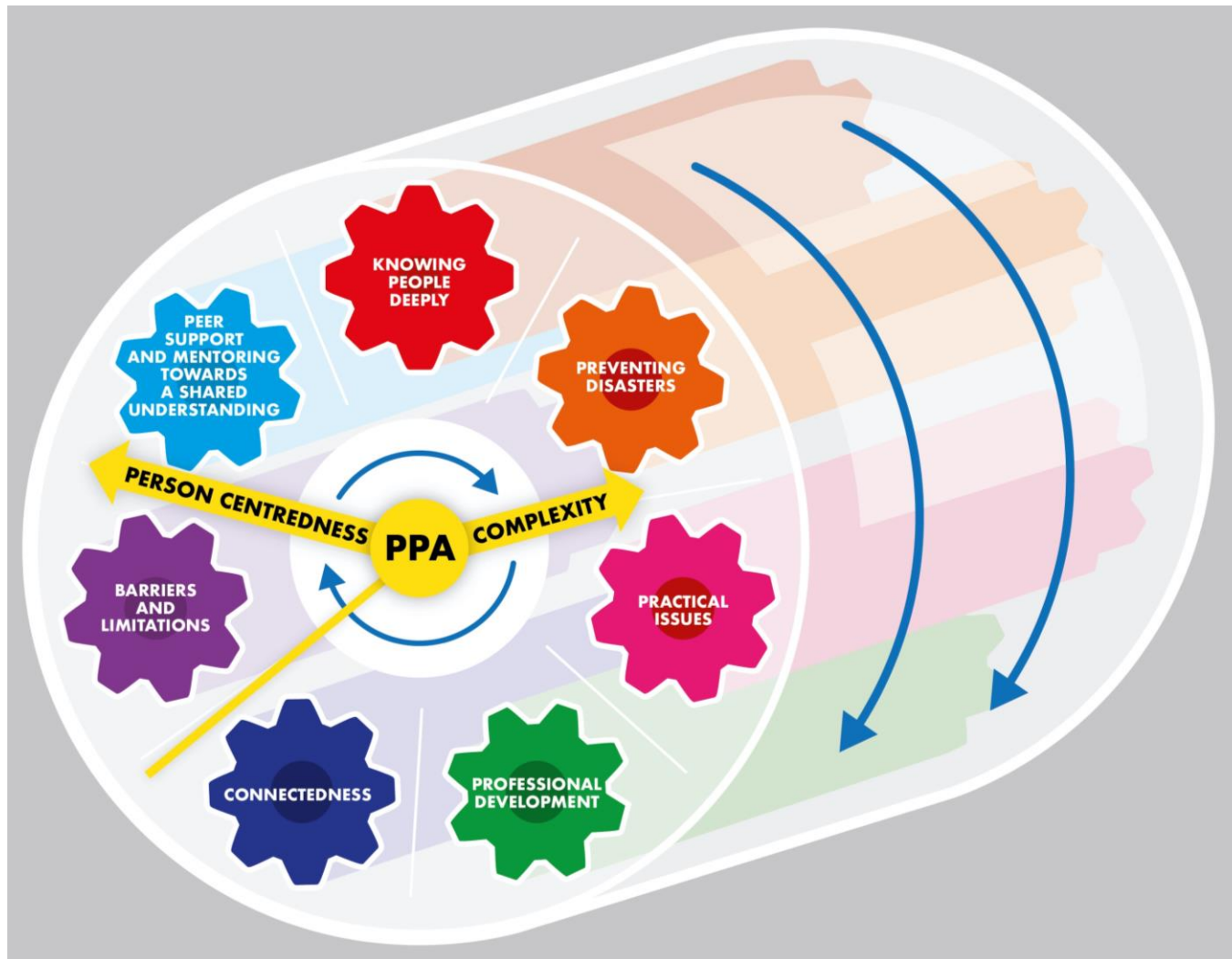


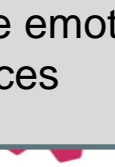






Table 3. Best practice principles when working with people with PPA.

Topic	Theme	Best practice principles
Get to know the person		<p>Know the person, their linguistic and cognitive strengths and weaknesses, their cultural and linguistic preferences, their occupational experiences, their family and support network</p> <p>Understand the person's diagnosis, presentation and its impact on that particular person with respect to their relationships and emotional wellbeing.</p> <p>Educate and support the person to understand their diagnosis, being mindful of the use of terminology and language.</p>
Include a significant other Address the emotional consequences		<p>Discuss issues such as finances and health care decisions, power of attorney and advance care planning so that people and families can be prepared for the future.</p> <p>Include a significant other, a partner or family member.</p> <p>Address the emotional and lifestyle consequences of living with PPA.</p>
Make time Plan review		<p>Get to know the person and set goals to guide therapy.</p> <p>Account the need to practice in a relevant and functional setting.</p> <p>Identify opportunities for groups, and meeting others with a similar condition.</p> <p>Plan to support the person over the long term through review (if appropriate) or refer people to seek re-referral.</p>
		<p>Familiarise yourself with the condition and prognosis (including the diversity and confusion in terminology and labels).</p> <p>Familiarise yourself with the current evidence-based interventions.</p> <p>Gain support to develop skills by seeking an appropriate mentor/supervisor.</p> <p>Develop counselling skills in this area.</p>
Share real case examples		<p>Familiarise yourselves with the available multidisciplinary team including: neurologists, psychologists, local speech and language therapists, social workers, occupational therapists, physiotherapists and dietitians.</p> <p>Refer people with PPA onto other professionals when they need support.</p> <p>Connect people with PPA to a social network with shared experiences.</p>
Seek an appropriate mentor/supervisor.		<p>Seek support, mentoring, and supervision for your own clinical practice and professional development.</p> <p>Advocate for funding or reimbursement of speech and language therapy for people with PPA.</p> <p>Inform your colleagues of the role of SLT/Ps working with people with PPA.</p>
Connect people		<p>Seek to influence SLT/P training and professional development opportunities.</p> <p>Share real case examples from clinical practice with other SLT/Ps through professional forums.</p> <p>Identify training opportunities.</p>

Intervention Research in PPA: Reviews

- Carthery-Goulart et al, 2013, Dementia and Neuropsychologica: **39** studies
- Cadorio et al, 2017, IJLCD: **25** studies
- Cotelli et al, 2020, Neuroscience and biobehavioural reviews: **50** studies
- Nissim et al, 2020, Brain Sciences: **8** studies (tDCS & TMS)
- Volkmer et al, 2020, Aging and Mental Health: **19** studies (functional interventions)
- Croot et al, under review: **103** studies (PPA & PPAOS)

Saw



Impairment



Aids



Environment

Word practice: the evidence



Saw

Used to cut through
wood

It's in my red toolbox

Pass me my saw

Jokel et al, 2014, Aphasiology

Cadorio et al, 2017, IJLCD

Croot, 2018, Sem in Speech and Language

Success and adherence

- Meaningful, personally relevant (words and images)
- Start early
- Continued daily practice
- Hierarchy of tasks including sentences and discourse
- Motivation and enthusiasm
- Supported by technology

Sentences: the evidence

- Script Training - high dosage and **personally relevant**

Football is a great sport.

My favourite team is Tottenham.

Harry Kane is a legend.

He played for England last year.

I love to watch football all the time.

Current research literature on functional communication interventions for people with PPA

- Key components of functional interventions for people with PPA include building on existing strategies and practising these with a CP
- Lack of robust designs and common outcome measures.

Functional Communication Therapy



(Mooney et al, 2018; Aphasiology)

MND Association @mndassoc

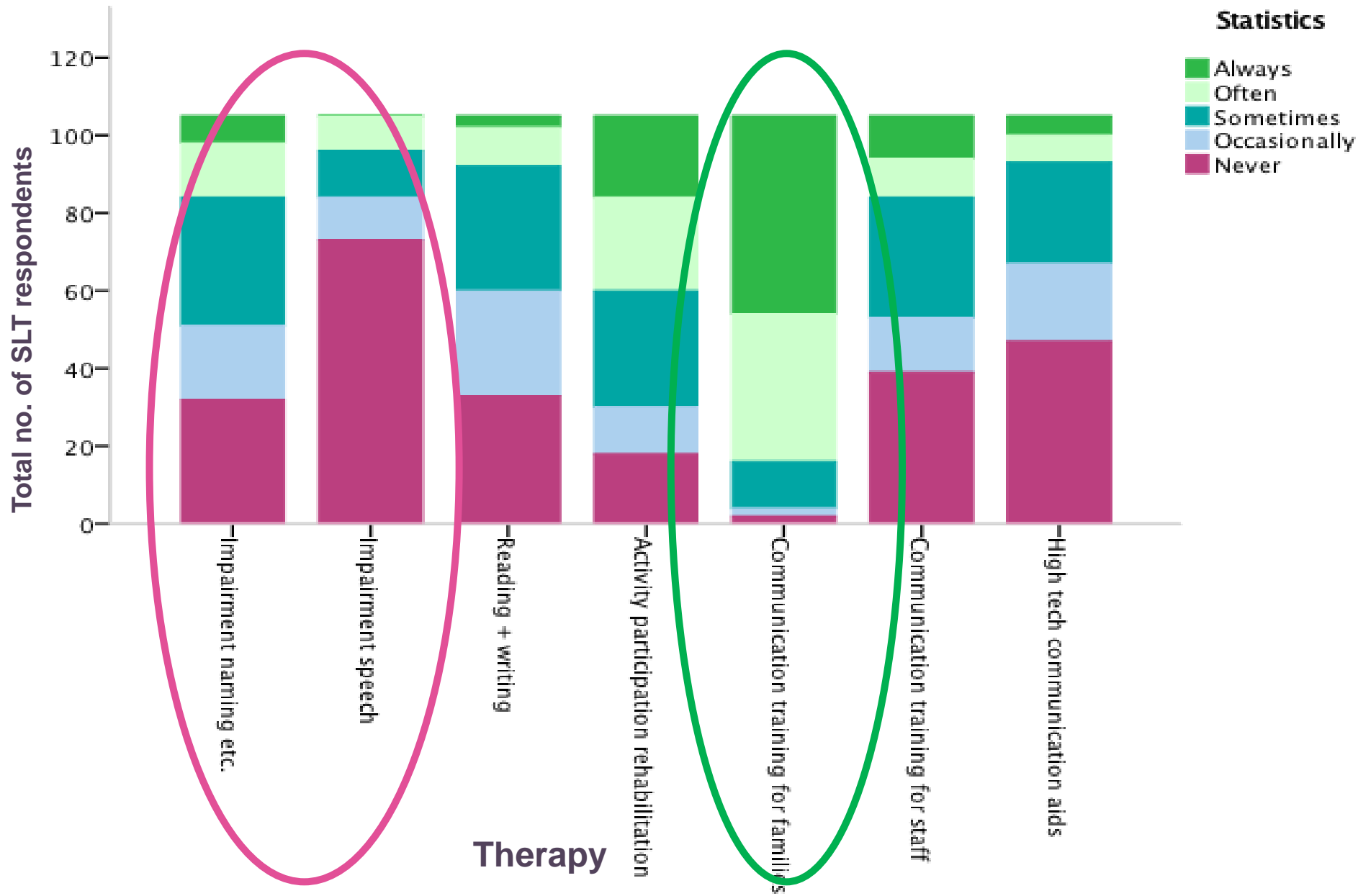
Great to see Richard Cave, a Speech and Language Therapist, feature on @BBCBreakfast this morning to chat about today's #IWillAlwaysBeMe launch.

This is an important piece of work.

#BBCBreakfast #MND

From BBC Breakfast

What communication therapy do SLTs use?





Conversational fingerprint of PPA

Summarised from Volkmer, A. (2013) Assessment and Therapy for Language and Cognitive Communication Difficulties in Dementia and Other Progressive Diseases. J&R Press, UK.

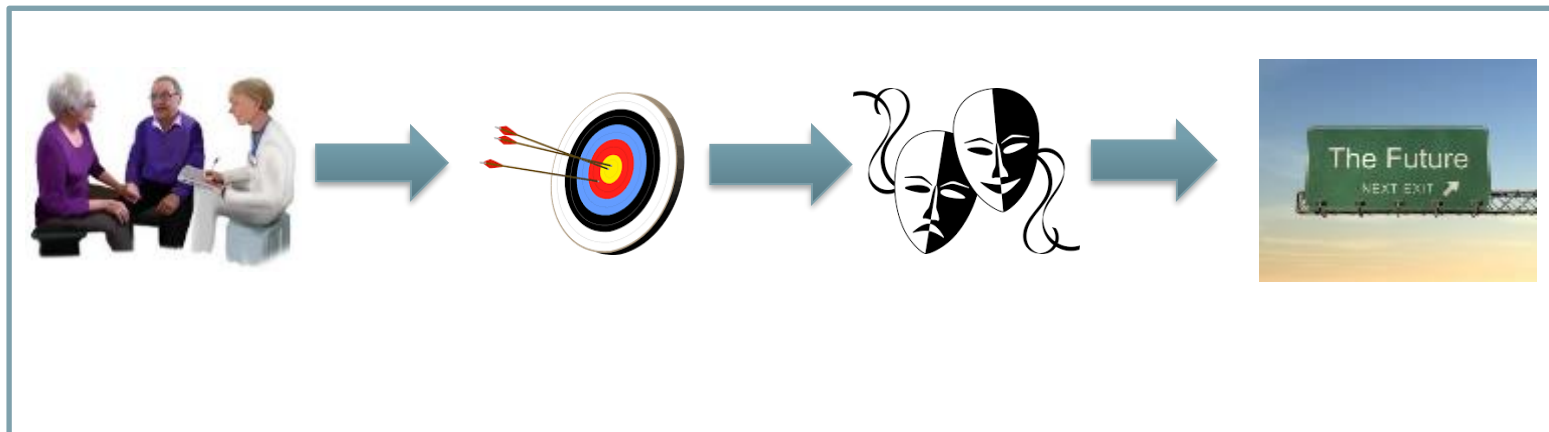
	Person with PPA	Conversation Partner
Facilitators to conversation	<p>Use of gesture and facial expression to support conversations</p> <p>Use of whole body language (enactment)</p> <p>Intent to interact and communicate (for ppl with svPPA and lvPPA and mild-mod nfvPPA)</p>	<p>Enabling time for turn initiation and turn completion</p> <p>Actively showing that a prior turn has been understood</p> <p>Signaling a problem with understanding at the first possible opportunity</p>
Barriers to conversation	<p>Finds topic initiation difficult</p> <p>Doesn't always recognise when conversation goes wrong (esp. lvPPA and svPPA)</p> <p>Lengthy pauses during turns (esp. lvPPA at mild-mod stages, and nfvPPA throughout)</p> <p>Lots of false starts and hesitations (esp. lvPPA at mild-mod stages, and nfvPPA throughout)</p> <p>Inappropriate changes of topic (esp. svPPA)</p> <p>Reduced awareness of the listener (esp. svPPA)</p>	<p>Correcting their partner's errors</p> <p>Creating 'learning events' or using 'test questions' - asking questions which both people in the conversation know the answer to, but the PwPPA may not have the language to answer</p> <p>Perception of communication behaviours as being 'on purpose' (e.g. he is lazy)</p> <p>Speaking on behalf of the person with PPA</p>





Better Conversations

with primary progressive aphasia



Session 1: What is conversation?


Session 2: Video analysis and goal setting

Session 3: Strategy Practice

Session 4: Problem solving and future planning

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Profile banner:  **Anna Volkmer**

COURSES

 **Better Conversations**
Better Conversations with Aphasia
a learning resource

Progress: 0 / 19 0%

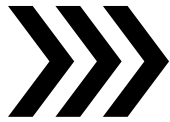
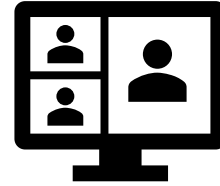
 **Better Conversations**
with primary progressive aphasia
Better Conversations with Primary Progressive Aphasia

Progress: 3 / 9 34%

Beeke, Volkmer, Farrington-Douglas, 2021, Perspectives
Volkmer et al, 2022, Neurocase
Volkmer et al, In Prep, Pilot and Feasibility Studies

Pilot results:

- 18 ppl with PPA & CPs completed the study
- Participants rated BCPPA positively
- Treatment fidelity was high
- Coded conversation behaviours targeted in therapy demonstrated change
- Of 30 goals set, 29 were achieved or overachieved
- The Aphasia Impact Questionnaire was identified as the preferred outcome measure and demonstrated a change in the intended direction



To use more clarification questions (to deal with the barrier of not understanding F.F. but letting this pass)



To try to focus more on the conversation while not doing something else at the same time (to deal with the barrier created by not being present in the room when F.F. had something to say)



To use gesture more to indicate I still have something to say (to deal with the barrier of long pauses in the conversation, and incomplete utterances)



To check H.H. is in the room before talking, either checking verbally or looking (to deal with the barrier created by speaking to H.H. when she was not in the room)

Conversation in PPA

“Most of her language skills, now, aren’t communication, they are needs, wants, information [...] Pure conversation is a lot more difficult, but it does happen. Um and it can be with humour, um and often um with, fear or concern” CP05

“[she’ll say] ‘have you seen this’ ‘well yes, I have actually’ [...] so we can have conversations like that, with a prompt in front of you like a newspaper article, or a picture.” CP03

“We’ve been married 48 years, we don’t have to say anything sometimes. Just a look will do it!” CP04

“The times when it was most difficult were the times, when we most wanted include her which is say, family events, when we’d all be talking [...] at the same time” CP12

“Therapy for me, and others to... speak, and talk in way that made it easier for her to join in” CP13

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In this recording, Helen speaks to Anna Volkmer about her diagnosis of mixed primary progressive aphasia.

Please note: the recording below includes the discussion of sensitive topics and may be distressing. Please email contact@raredementiasupport.org if you would like to talk to somebody about any of the issues raised.



<https://www.raredementiasupport.org/living-with-a-diagnosis-of-mixed-primary-progressive-aphasia/>