

Painting a common future in Alzheimer's disease





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Foreword from the F.A.S.T. Council co-chairs

Alzheimer's disease (AD) is an overwhelming condition that presents unique challenges to people living with AD (PLWA), their loved ones, their care partners, and the scientific community. These range from lack of understanding of the condition to difficulty in clinical trial recruitment and can impact not only the ways in which PLWA are cared for but also the successful development of novel therapies.

As AD's global impact continues to increase, it is crucial that we, as a community, come together to address this immense public health issue. Recognising this, the Finding Alzheimer's Solutions Together (F.A.S.T.) Council was formed to bring AD patient organisations (POs) and Roche together with the aim of better understanding the perspectives and needs of AD patient communities. The F.A.S.T. Council provided the opportunity to discuss potential areas for collaboration with the pharmaceutical industry that could help improve the care provided to PLWA and inform scientific breakthroughs. Following the disappointing news in November 2022 that Roche's investigational molecule for the treatment of AD had failed in its phase III clinical trials, the F.A.S.T. Council met in January 2023 to discuss what the organisations represented wanted and needed from Roche in 2023. The following questions were asked:

- Given the situation, do you want to continue working together in the F.A.S.T. Council?
- If so, what should the focus be given where Roche is in the clinical development process?
- To what extent would you like to remain involved in Roche's activities?

The group unanimously agreed that it was crucial that Roche supported the publication and dissemination of the learnings, recommendations and outputs from the F.A.S.T. Council.

The group also agreed to continue working with the F.A.S.T. Council with an important focus on research and development, especially on supporting the design and implementation of trials, keeping participants and their study partners at the heart of the programme, and focusing on tactics to engage more efficiently with underrepresented populations.

As such, this report represents the conclusion of the F.A.S.T. Council's work, outlines the learnings gathered over the past three years and provides recommendations on:

- Best practices to ensure meaningful collaborative working between the pharmaceutical industry and POs
- Optimising the PLWA and care partner journeys
- Raising awareness and advocating for better care
- Conducting inclusive clinical trials

We hope that the learnings set out in this report will be leveraged and taken forward by other organisations from across the AD community. We sincerely believe that only through collaboration between industry, POs and the whole AD community will we give ourselves the best chance to improve the lives of PLWA and their care partners, and to discover and operationalise the treatments and diagnostics needed to, ultimately, begin to treat this devastating condition.

The F.A.S.T. Council, is sponsored by Roche and its members include:





Acknowledgements

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We would like to thank the team from Ipsos, a global market research consultancy, who supported the work of the F.A.S.T. Council.

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F.A.S.T. Council members

(Outlined in alphabetical order)

Alzheimer Europe, Luxembourg

Alzheimer Europe (AE) is the European umbrella organisation of 35 national Alzheimer's associations from 32 countries. AE defines its mission as “*changing perceptions, practice and policy in order to improve the lives of people affected by dementia*”. AE achieves this mission by providing a voice to people with dementia and their carers, making dementia a European priority, changing perceptions, and combating stigma, raising awareness of brain health and prevention, strengthening the European dementia movement, and supporting dementia research.

Alzheimer's Disease International, UK

Alzheimer's Disease International (ADI) is the international federation of Alzheimer's and dementia associations with 105 members globally and 25 in development. Its vision is risk reduction, timely diagnosis, care, and inclusion today, and cure tomorrow. ADI believes that tackling dementia requires efforts at global, regional, and local levels and works by empowering Alzheimer's and dementia associations to advocate for dementia as a national priority, to raise awareness and to offer care and support for people with dementia and their care partners. Globally, ADI strives to focus attention on dementia, maintain it as a global health priority, campaign for better policy from governments and encourage investment and innovation in dementia research.

Alzheimer's Hellas, Greece

Founded in 1995 by care partners and medical professionals, the Greek Association of Alzheimer's Disease and Related Disorders (Alzheimer's Hellas) is a not-for-profit organisation that currently operates two day-care centres in Thessaloniki as well as a dementia palliative care setting and has over 5,000 members. The Association's aim is to offer advice on the care of those living with Alzheimer's; information, support and services for the people affected and their families; help to those living with Alzheimer's to reduce the social, economic, and emotional cost deriving from the long-term care of people suffering from dementia; providing raising awareness seminars to health professionals as well as general population and publicise the social needs of the population affected.

Alzheimer Nederland, Netherlands

Alzheimer Nederland is committed to working towards a future without dementia and a better quality of life for people with dementia and their informal carers. Alzheimer Nederland conducts work across five key pillars: research; support; advocacy; dementia-friendly societies; and education and information.

CanAge: Canada's National Seniors Advocacy Organization, Canada

CanAge is Canada's national seniors' advocacy organisation, working to improve the lives of older adults through advocacy, policy, and community engagement.

Federação Brasileira das Associações de Alzheimer (Febraz), Brazil

Febraz brings together four Alzheimer's associations – Associação Brasileira de Alzheimer, Associação de Parentes e Amigos de Pessoas com Alzheimer, Instituto Alzheimer Brasil and Instituto Não Me Esqueças. Febraz has branches in more than 23 Brazilian states and works to empower its member associations, share best practice, advocate for the rights of people living with dementia and their care partners, and develop campaigns to eliminate the stigma of the disease.

Roche, Switzerland

Roche is a pioneer in pharmaceuticals and diagnostics, focused on advancing science to improve people's lives and is committed to working to improve the diagnosis, treatment and care of people living with Alzheimer's and dementia. Roche engaged with people living with Alzheimer's, their care and study partners, global and local Alzheimer's patient organisations and healthcare professionals to understand the experience of PLWA and their care partners and uncover solutions that can improve access to high-quality care for these people.

Shanghai Jianai Charity Organization, China

Jian Ai Charity is a non-profit organisation in Shanghai, with a focus on the brain health of older people. Since being established in 2013, Jian Ai Charity has been an active advocate of early prevention and intervention for cognitive impairment. Primarily focusing on dementia, from 2013 to 2016, its community-based initiatives covered dementia awareness and friendliness promotion, risk reduction, screening test, non-pharmacological intervention, and respite care. In 2017, Jian Ai Charity strategically narrowed its focus on the early stage of disease progression – mild cognitive impairment.

Stiftelsen Alois Alzheimer, Sweden

Stiftelsen Alois Alzheimer was founded in 2012 in Lund, and is now based in Stockholm. The foundation supports clinical research for neurodegenerative diseases, particularly Alzheimer's disease. Through supporting research, the foundation focuses on improving the memory testing process, treatment methods and supporting specialist memory physicians for people with early onset Alzheimer's and mild cognitive impairment - including people with Down's syndrome. The foundation collaborates with likeminded social entrepreneurs and non-governmental organisations in Sweden, Europe and across the world and contributes to patient engagement issues with relevant EU-related authorities and international industry partners.

Interview with Wendy Weidner and Jannice Roeser



Wendy Weidner,
Head of Research and Publications,
Alzheimer's Disease International



Jannice Roeser,
Global Patient Partnership Leader,
F. Hoffmann-La Roche

Why is it important for the pharmaceutical industry and the patient community to work together in Alzheimer's disease?

Wendy: Alzheimer's disease (AD) is a complex condition that impacts so much of a person's life – their physical health, mental wellbeing, independence and relationships. Our last two World Alzheimer Reports revealed an equally complex journey for people hoping to access a diagnosis as well as post-diagnostic treatment, care and support. Complex issues require the careful and thoughtful development of solutions that pull insights from many areas of expertise. This is why the collective knowledge exchange of the Finding Alzheimer's Solutions Together (F.A.S.T.) Council has been so inspiring.

Patient organisations (POs), like many of us who form part of the F.A.S.T. Council, work alongside people living with dementia and their care partners and support them throughout their entire journey of dementia – from pre-diagnosis, through to diagnosis and their care journey, into end of life. An important aspect of our work is linking in with new research or initiatives that can provide treatment – whether that is around care or a medicine.

Working collaboratively with industry is a two-way street. We benefit by learning about new treatments and clinical trials, enabling us to disseminate this information to our members and communities so they have access to the latest research around timely diagnosis and treatment options. Equally, we are able to represent the diverse voices of people living with AD (PLWA) and their care partners when advising on important issues such as language, equitable access, and safety.

Working with industry is one facet of our work, but an important one. We both have important roles to play in this field – drug discovery is absolutely necessary if we are to give people hope and integral to that is ensuring that the voices of people living with AD and their families are included in the drug development and treatment distribution process.

Jannice: Roche sees collaboration between the pharmaceutical industry and the patient community, including POs and care partners, as vital in addressing the challenges posed by AD. Through its extensive research and development efforts, the pharmaceutical industry can identify potential treatments and therapies that may alleviate symptoms, slow down disease progression, or even eventually prevent AD entirely. Collaboration with the patient community ensures that these industry efforts align with the real-world needs and experiences of those living with the disease. Patient insights and perspectives play a crucial role in shaping research priorities, clinical trial design, and treatment approaches, enhancing the overall effectiveness and relevance of pharmaceutical interventions.

Over the last few years in particular, we have been able to go beyond our research and development role and co-create solutions that are tailored to the specific needs of PLWA and their care partners. Ultimately, this has led to a better understanding of what we need to do to improve outcomes and of what our role is in enabling better care for AD.

How did the collaboration through the F.A.S.T. Council add value to Roche and Alzheimer Disease International (ADI)'s respective work?

Jannice: For Roche, this collaboration provided an ongoing dialogue with POs from across the world, enabling us to understand the viewpoint of PLWA and their partners as well as supporting the development of optimal treatment pathways for new AD therapies. Through the F.A.S.T. Council, we welcomed the opportunity to discuss the myriad of complex issues that affect PLWA and their families, who currently have few treatment options and face many frustrations in seeking a diagnosis and support. By establishing this forum, Roche created the time and space for all of us involved to better understand each other's work and to carefully consider how we could enhance both our own and each other's impact while ensuring that we put the PLWA and their loved ones first and foremost. I truly believe this has ultimately inspired us to work together towards holistic solutions that benefit the broader AD community.

Wendy: Being part of the F.A.S.T. Council enabled ADI to regularly meet with a diverse group of colleagues working in the field of AD and dementia. We were able to explore new areas of research and other important projects that Council members were pursuing; share these learnings with our members; and, whenever possible, involve some of our members in these discussions. Importantly, it gave us the opportunity to provide valuable input on how to ensure the language used around AD is inclusive and how to improve access to upcoming research and clinical trials for all PLWA.

What are the benefits of collaborative working between the pharmaceutical industry and patient organisations?

Wendy: The benefits are many, but I will sum them up in three points. First, I don't think we can underestimate the importance of the knowledge exchange aspect of our collaborative working. We shared information and resources, provided advice, posed questions, debated issues and enhanced and improved each other's work through sharing ideas. Second, the regularity of our meetings meant that there was a real momentum and impact focus to our work together. Finally, it has been fun. We've got to know each other and to share a small window into not only our work, but into our lives. And it's made our collaboration all the richer.

Jannice: Further to Wendy's points, we see collaborative working between the pharmaceutical industry and POs as crucial to enabling an inclusive and collaborative approach to dementia and AD care. By actively involving the patient community, including POs, in research prioritization, clinical trial design and decision-making processes,

we can jointly improve the way we run clinical trials, enhance the participant experience while getting meaningful data to assess efficacy of new treatments. Collaborating also enriches the exchange of knowledge and resources, improves public education and awareness, ultimately with the objective of enabling greater availability of innovative therapies and solutions for PLWA, their families and care partners.

What are the main considerations for each side to take into these types of partnerships?

Jannice: It is crucial to prioritise open and transparent communication. We need to genuinely listen to, and respect, the perspectives and experiences of the patient community, recognising their invaluable expertise and insights. We also have the onus to ensure ethical guidelines are followed, safeguarding privacy and always prioritising the best interests of the community. It is equally important for the patient community to understand their responsibilities towards the pharmaceutical industry, particularly in safeguarding confidentiality to allow for innovation. By fostering partnerships based on trust, fairness, and mutual benefit, we can cultivate long-term collaborations that drive meaningful advancements in AD research and care.

Wendy: In addition to Jannice's points, good collaborations require a time commitment in order to be successful, so it's important to be aware of this and to be prepared. Equally, it's important to ensure the work doesn't take place in a vacuum and that you make an effort to share it more widely and pass on the knowledge to have a greater impact.

How can the work of the F.A.S.T. Council shape the future?

Jannice: We are immensely grateful to the F.A.S.T. Council for their outstanding work and collaborative spirit throughout our partnership. We are hopeful the work undertaken will serve as a catalyst, inspiring other actors in the AD environment to leverage the learnings and actively support the patient community. Our goal is to openly encourage and foster collaboration and collective efforts towards achieving the best outcomes for PLWA and their loved ones.

Wendy: It is my sincere hope that we can continue to build upon the collaborations we've started during the F.A.S.T. Council. We have contributed to some important pieces of work, and I hope that we can continue to disseminate these. A theme that became evident during the F.A.S.T. Council was the importance of preparing global health systems so that they can better support PLWA, their families and care partners. I hope that we can continue to collaborate on this (and other issues), finding effective ways to bring together our collective knowledge and expertise to make tangible, transformative, and sustainable change for the better in this complex area of AD and dementia.

Executive summary of recommendations



The topline recommendations from this report are summarised below. Recommendations are divided between those for forming and running collaborations including patient organisation representatives, taken from the Finding Alzheimer's Solutions Together (F.A.S.T.) Council's experience, and specific best practice recommendations to improve research and care in Alzheimer's disease (AD), developed during the course of the Council's work.

Recommendations to ensure meaningful collaborative working between the pharmaceutical industry and patient organisations

- Initial scoping exercises are essential to understand the members' interest in committing time to a council, as well as the opportunities and barriers they see to participation.
- Scoping should both seek to gauge consensus on key areas that the council will work on – for the F.A.S.T. Council, this meant questions on the experiences, views and involvement of people living with AD (PLWA) and their care partners – and to understand practical questions like the amount of time patient organisation representatives are able to contribute to the Council and the optimal meeting cadence.
- Co-creation should be the core working approach to all of the council's activities – including developing the name, objectives and values.
- Setting clear objectives and values for the council is a crucial step for setting expectations from members and helping to foster a true sense of partnership and co-ownership amongst members. Core values of trust, transparency, integrity, and independence will apply to every council and its work, including disclosure around honoraria or other payments made to representatives.
- When approaching organisations to join a council, every effort should be made to ensure that diverse geographies and areas of interest are represented.
- Representatives from patient organisations can come from a diverse range of profiles (PLWA, care partners, family members of PLWA, or patient organisation professionals, etc), so content and meetings will have to be tailored appropriately according to be different backgrounds, expertise and cultures present.
- To make the council as accessible as possible, virtual meetings should be considered as they can facilitate collaboration at the international scale and easily allow for a variety of approaches to be used, including time for individual reflection and group breakout sessions. Nonetheless, in-person collaboration can have several benefits and, if possible, should be accommodated.
- Throughout the life of the council, the group should regularly return to the core values that brought them together to check that activities still align with the underlying reasons for working together.
- The council should respect members' time, ideas and enthusiasm, ensure that meetings are as efficient as possible and that actions are delivered productively, and avoid any duplication of effort.
- A shared culture should be fostered at every opportunity, including by encouraging participants to keep their cameras on during meetings.

Care pathways

New pathways that better support PLWA and their care partners should be developed considering the emergence of disease modifying therapies for AD. Whilst the development of these pathways will need to be clinically driven, PLWA and their care partners must be co-partners throughout. Detailed pathway recommendations are included in the [Optimising the person living with Alzheimer's disease and care partner journeys](#) section of this report, but crucial points are summarised below:

Pre-diagnosis

- Healthcare systems should work with patient organisations to organise public awareness campaigns to educate the public on the early symptoms of AD.
- Primary care clinicians should be supported to screen and appropriately refer people with suspected AD in new, more efficient, and effective ways. This could include digital and telemedicine approaches.

Diagnosis

- Clinicians should receive education on AD – focusing on the importance of receiving and communicating a timely diagnosis and the need for onward referrals to specialist care.
- Research should continue into digital biomarkers, which can detect biological changes before cognitive impairment occurs.

Treatment

- The whole patient community should receive additional support in preparation for the arrival of disease modifying therapies. People eligible for treatment will need to be prepared, whilst ineligible people will need additional counselling and support.

Inclusive language

- Using language that resonates with PLWA and their care partners is essential to facilitating both clinical trial participation and productive relationships with treating clinicians. Language should be inclusive, empowering and recognise the changing emotional and physical pathway PLWA and their care partners are on. These considerations have been widely recognised across the AD community, such as in the [Guidelines for the ethical and inclusive communication about/portrayal of dementia and people with dementia](#), co-authored by Alzheimer Europe and the European Working Group of People with Dementia.
- Appropriate language is especially important when discussing possible side-effects from treatments, including amyloid-related imaging abnormalities (ARIA), whether in clinical practice or as part of a trial. The language used should ensure PLWA can make informed decisions about their treatment and clinical trial participation.
- It should be noted that the F.A.S.T Council made every effort to develop inclusive language that is flexible and contextually appropriate and that could be used by the AD community across the world. However, differences remain between cultures, geographies and native languages which can alter the understanding and nuance of the language proposed.

Addressing key policy challenges in AD

- National governments should commit to developing national dementia plans which drive the adoption and implementation of improved and timely diagnoses, care, support and treatment for PLWA. Plans should incorporate multi-sectoral partnerships to ensure the whole community is committed to their delivery.
- The progress against policy goals and targets should be regularly measured and reported on.

The role industry and other stakeholders can play in supporting patient organisations in driving policy change

- The pharmaceutical industry can help elevate and amplify the patient perspective in policy debates through:
 - Collaborating and co-creating new evidence and tools that can be used by the AD community in policy advocacy.
 - Partnering with the AD community to mobilise and advance a set of shared policy priorities and policy asks.
 - Amplifying and supporting the AD community in their policy and political advocacy efforts.
 - Being an active contributor to AD policy debates.
 - Building the case for greater action and collaboration by providing data and insights on the scale of the problem and through the development of solutions.

Conducting inclusive clinical trials

- The experience of PLWA and their care partners should be at the heart of clinical trial design and delivery. Detailed recommendations are available in the report [Integrating the perspectives of people living with Alzheimer's disease and their study partners into clinical trial development](#).

Making the case for collaboration in Alzheimer's disease



Alzheimer's disease (AD) is the most common form of dementia, affecting up to 70% of the 55 million people living with dementia worldwide today. This figure is expected to increase, as each year, there are nearly 10 million new cases of dementia.¹²

In addition to its wide global impact, AD is devastating to those who live with it (PLWA) and their care partners – with symptoms including memory and cognitive loss, and personality and behaviour changes.^{3,4} Although these symptoms can be temporarily relieved through disease management and medicines, there are still no treatments to prevent or cure AD.³ The AD community also experiences significant gaps in the care pathway, such as lack of funding for, and access to, specialist testing;^{5,6} absence of, and uneven access to, centralised post-diagnostic knowledge, support, counselling and care; lack of appropriate clinical trial infrastructure; and scarcity in patient registries to support rapid enrolment in clinical trials.^{2,7} The anticipated, widespread arrival of disease modifying treatments (DMTs) also highlights further gaps in the care pathway, such as a shortage of clinical assessment tools that measure the effectiveness of therapies in early-stage AD.⁸

The scale and complexity of AD thus calls for broad, cross-sectoral collaboration that mobilises the skills, knowledge, and experiences of the AD community to better address this unmet need.

PLWA, care partners and patient organisations (POs) are key stakeholders in this process as they can help provide a true picture of what it is like to live with AD; how care is delivered and how it impacts PLWA, their

care partners, and their families; and how medical treatments and psychosocial interventions can improve quality of life.⁹ Listening to their experiences and working collaboratively with them has the potential to help destigmatise the condition and improve disease management in 'dementia friendly' societies that respect PLWA's human and civil rights, and shape the future of research.

The pharmaceutical industry is also striving to improve the ecosystem surrounding AD, and now more than ever there is an opportunity to together explore how a holistic understanding of the unmet need in AD can help find solutions that enable the delivery of more inclusive care and research.

With this in mind, Roche brought together the Finding Alzheimer's Solutions Together (F.A.S.T.) Council, a bi-annual council where AD POs from around the world and Roche discussed areas of collaboration and worked together to understand the perspectives and needs of PLWA and their care and study partners.^{2,6} This report outlines the insights gathered by the Council since 2020, as well as recommendations on how POs can successfully collaborate with industry to deliver patient-focused solutions.

It should be noted that these recommendations may not always be fully reflective of the needs of every PLWA or care partner. AD is a unique journey that is dependent on many factors, including the stage of the disease and the circumstances of the PLWA and care partners. Therefore, it is key that readers fully consider and appreciate the local and personal contexts in which they operate.

Roche and the F.A.S.T. Council case study

Background on the F.A.S.T. Council



In early 2020, Roche was looking to expand its understanding of the context surrounding Alzheimer's disease (AD), to shed light on the unmet needs of people living with AD (PLWA) and to identify potential solutions where Roche could add value.

Given this, Roche conducted an online survey with care partners and PLWA and held a workshop with several patient organisations (POs), including Alzheimer Europe, Alzheimer's Disease International and Alzheimer's Hellas, to better understand the implications of AD on care partners' and PLWA's lives.

This initial scoping work used the following research objectives to generate an understanding of PLWA's and care partners' perspectives:

- What does it mean to live with AD?
- What is the impact of AD on PLWA's and care partners' lives (emotionally and socially)?
- What are PLWA's and care partners' expectations, hopes and concerns towards AD treatment, specifically relating to disease modifying therapies (DMTs)?
- What are PLWA's and care partners' priorities, areas of interest and needs?
- How could these unmet needs be addressed to make a difference in PLWA's and care partners' lives?

Following this initial workshop, the Finding Alzheimer's Solutions Together (F.A.S.T.) Council was established – the organisation and funding of which was led by Roche. The Council met bi-annually, and a list of its current members can be found in the [F.A.S.T. Council members](#) section of this report.

In acknowledgement of the breadth of experiences of PLWA and their care partners, the F.A.S.T. Council adopted the primary objective of better understanding the perspectives and needs of AD patient communities. This enabled the Council to identify and prioritise the following areas for collaboration:

- Disease awareness
- Early detection
- Diagnosis
- Clinical trials information
- Access to new therapies
- Policy and political advocacy
- Health system preparedness

Throughout its collaboration, the Council maintained a series of core values – trust, transparency, integrity, and independence – and developed ways of working and knowledge sharing that considered the challenges faced by the AD community. It also developed several resources and proposed solutions focused on strengthening the support provided to the AD community, improving inclusive research in AD, and enhancing advocacy and policy efforts of AD communities around the world. These are outlined in greater detail in the [Learnings and recommendations from the F.A.S.T. Council](#) section of this report.

Running of F.A.S.T. Council meetings to ensure collaborative working

The F.A.S.T. Council is built upon a collaborative approach to ensure effective use of time, open communication, reduction in duplication of efforts and to improve relationships between members. As the Council captured knowledge and learnings from across the world, it was essential to work in a way that allowed members to bring their insights and learn from one another. F.A.S.T. Council meetings were thus conducted twice a year in a virtual format and the following tools were used:

1. **Shared decision making** – co-created the Council’s name with all members, formalised the common goals and values of the Council, and developed a distinct identity that was adopted in the creation and distribution of the Council’s outputs
2. **Digital engagement** – used online bulletin boards, digital forms, polls and video sharing
3. **Individual reflection** – leveraged the chat function on video platforms, encouraged active and passive listening, and promoted space for quiet reflective thinking as the topics discussed can be emotionally difficult and many participants shared personal experiences of loved ones with AD
4. **Group breakout sessions** – encouraged members to provide insights from their work in small peer groups, with all members taking an active role in providing feedback
5. **Accessible materials** – captured the outputs from F.A.S.T. Council meetings as illustrations and clarified the Council’s purpose by representing its vision in an easy-to-understand format, to ensure these could be easily accessible by the AD community

While a range of less structured interactions, such as the group breakout sessions detailed above, helped the Council capture authentic feedback, each meeting was guided by the below objectives, which provided structure to the collaborative efforts and ensured clarity of purpose.

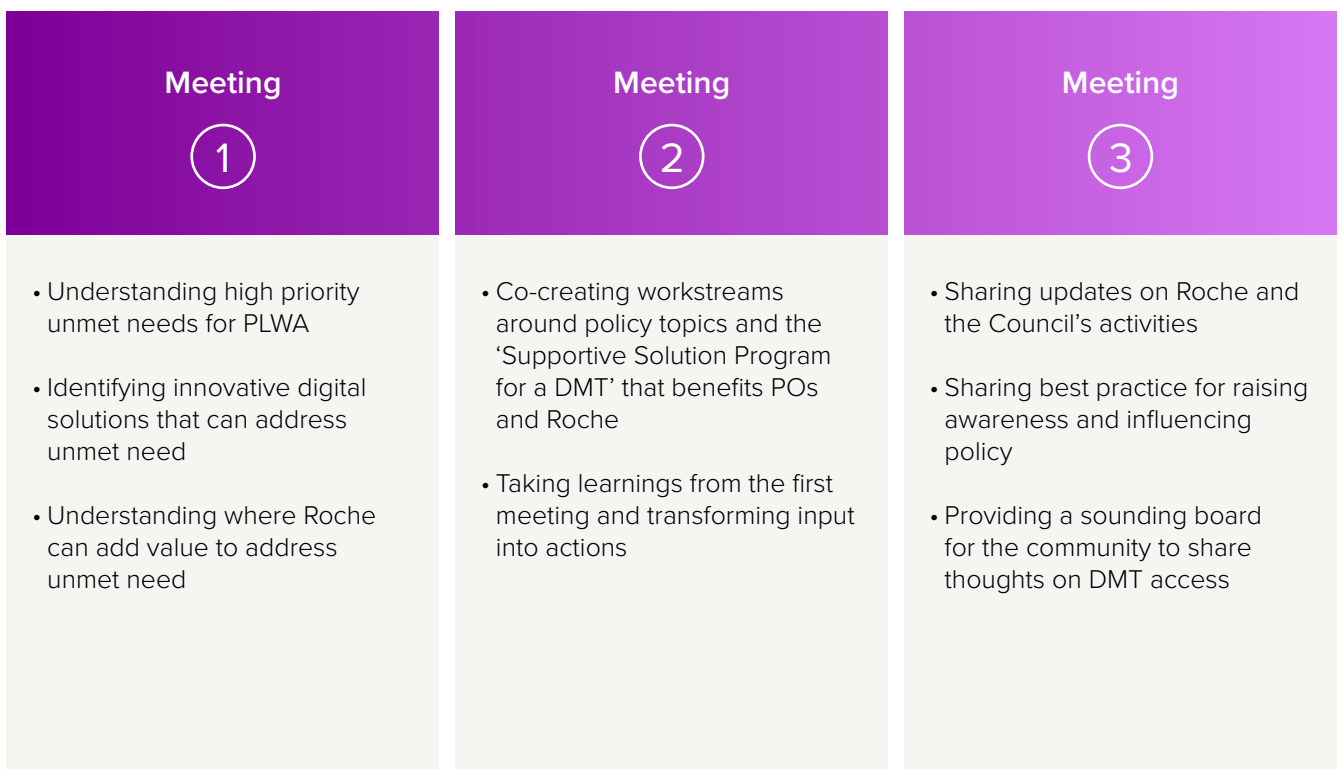


Figure 1. Overview of the objectives of each F.A.S.T. Council meeting



Meeting

4

- Deep diving into hot topics and advocacy efforts of members
- Learning and exchanging best practice with PO co-chairs and Council members
- Enabling the community to share thoughts on Roche's AD initiatives
- Demonstrating how feedback received on Roche-led initiatives was incorporated

Realignment meeting

>

- Held in January 2023 after the disappointing news that Roche's investigational molecule had failed phase III clinical trials
- Considered the future of the F.A.S.T. Council and agreed to develop this report

Meeting

5

- Sharing updates on Roche's research programmes
- Discussing ongoing F.A.S.T. collaboration and publications
- Agreeing ways to continue positive collaboration in future

Learnings and recommendations from the F.A.S.T. Council

Recommendations to ensure meaningful collaborative working between the pharmaceutical industry and patient organisations

As outlined in the previous section, a collaborative approach was a key pillar of the ways of working of the Finding Alzheimer's Solutions Together (F.A.S.T.) Council. To ensure the development of creative outputs and meaningful relationships between members was achieved, this collaboration was based on mutual understanding and undertaken with intention and care. To achieve this the following was agreed upon by all members:

- Set of guiding values
- Culture principles
- Engagement principles
- Council's objectives and members' expectations

Values

When setting up the Council, it was acknowledged that whilst some of the interests of patient organisations (POs) and Roche are distinct, many are shared. To guide collaboration towards areas that all members wanted to prioritise and that most benefited people living with Alzheimer's (PLWA), the Council defined a set of guiding values for their collaboration – trust, transparency, integrity, and independence.

These values were implemented in practice by ensuring a culture that is open, inclusive, personal and personable, interactive, and objective-driven – positioning the F.A.S.T. Council to turn momentum into action.

Culture principles

Most F.A.S.T. Council meetings took place during the COVID-19 pandemic, so it was particularly important to create a culture that ensured meaningful collaboration when all contact had to be virtual. This included efforts to:

- Encourage participants to use their video function, as it can lead to more effective meetings¹⁰
- Create open feedback loops, including by using a range of learning methods and digital tools to measure how participants experience the level of effectiveness and inclusiveness^{6,11}
- Share best practices, to enable a deeper understanding of the Council's work towards its overall objectives, as well as each of the members' aims and purposes as distinct organisations





Engagement principles

Establishing buy-in from participants on the benefits of remote meetings, as well as the broader objectives of the Council, was also key to the F.A.S.T. Council's work. Roche was keenly aware that some Council members were balancing multiple responsibilities – for example caring for someone with Alzheimer's disease (AD) alongside professional PO responsibilities – meaning that while an environment for productive discussion was paramount, the Council needed to be flexible to accommodate the needs of participants.

The COVID-19 pandemic produced a wealth of research on best practice for encouraging virtual participants to bring their most collaborative selves to meetings, which were adopted by the F.A.S.T. Council.¹² At the beginning of, and throughout, Council meetings:

Participants were encouraged to:

- Prepare for meetings by organising a quiet workspace while embracing any unavoidable distractions
- Make their space as comfortable as possible (e.g. by having drinks and snacks to hand)

Meetings were encouraged to be/include:

- Compact and focused
- Breakout sessions and regular check-ins to see how participants were finding the experience and when it might be appropriate to schedule breaks
- Interactive ice-breaker activities, to ensure rapport was built between participants

Defining objectives and setting expectations

When defining the objectives of the Council, members were asked to highlight areas they would like to prioritise and concerns they would like to address through the Council's work. Once these were identified, and as outlined in the previous section, a set of dedicated areas of focus was defined which included AD awareness and political and healthcare system reform.

It was, however, critical to bring a realistic perspective to the outputs of the collaboration to ensure that patient communities didn't feel overwhelmed. This was done through:

- Prioritising initiatives which would have the most impact to PLWA and the AD community
- Leveraging work, from the AD community, that was already available
- Agreeing on the roles and responsibilities of Council members, for each of the identified areas for collaboration

Recommendations to improve research and care in Alzheimer's disease

Optimising the Person Living with Alzheimer's and care partner journeys

One of the areas of focus for the F.A.S.T. Council was to better understand the current challenges experienced by PLWA, their families and care partners. Following an initial discussion these were identified as including:

- AD being emotionally, physically, and financially taxing¹³
- PLWA requiring ongoing care, and it has been estimated that 75% of caregiving for PLWA is provided by informal care partners¹³
- Care partners needing to stop or reduce their work hours to provide care for PLWA, as this can include assisting with activities of daily living, taking on financial responsibilities, advocating for PLWA in healthcare settings, ensuring medication compliance, managing behavioural symptoms and organising external support (such as in-home care)¹³
- Lack of access to appropriate diagnosis, with approximately only one quarter of people with dementia having received a diagnosis worldwide¹⁴
- Lack of Disease Modifying Treatments (DMTs) and joined up care pathways, meaning that often PLWA and their care partners do not receive the support they need



The current PLWA and care partner journey

Following this discussion and based on additional insights collated from the AD community, the current PLWA and care partner journey were compiled, capturing the challenges both face regularly across each stage of their journey.^{15,16}

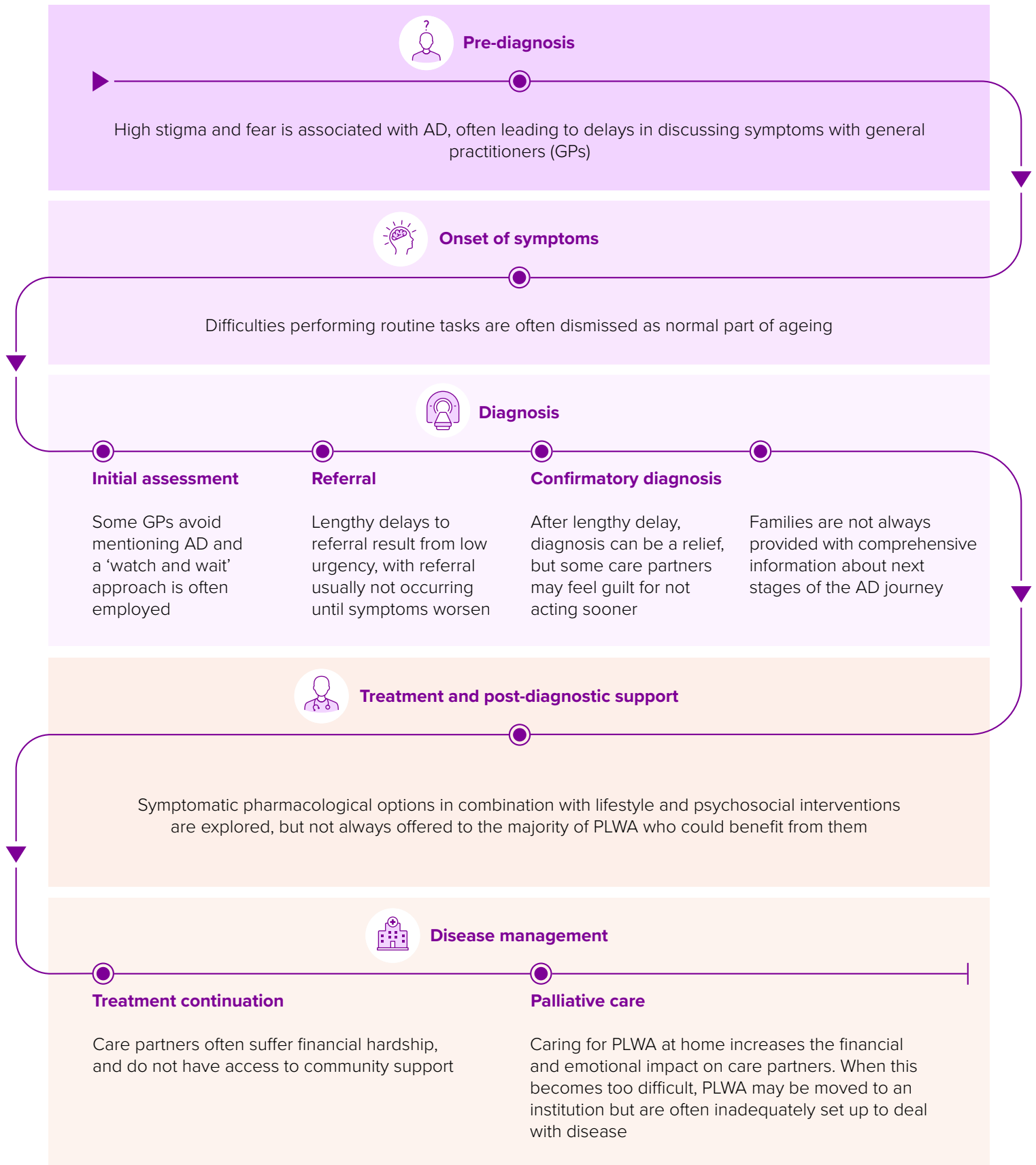


Figure 2. Overview of barriers faced by PLWA and their care partners across the AD patient journey

The optimal PLWA and care partner journey

Following the identification of several challenges PLWA and care partners experience across their AD journey, the F.A.S.T. Council proposed a more optimal pathway for PLWA and their care partners – which has been detailed below. It should be noted that this pathway is intrinsically linked to the potential arrival of a DMT for AD.

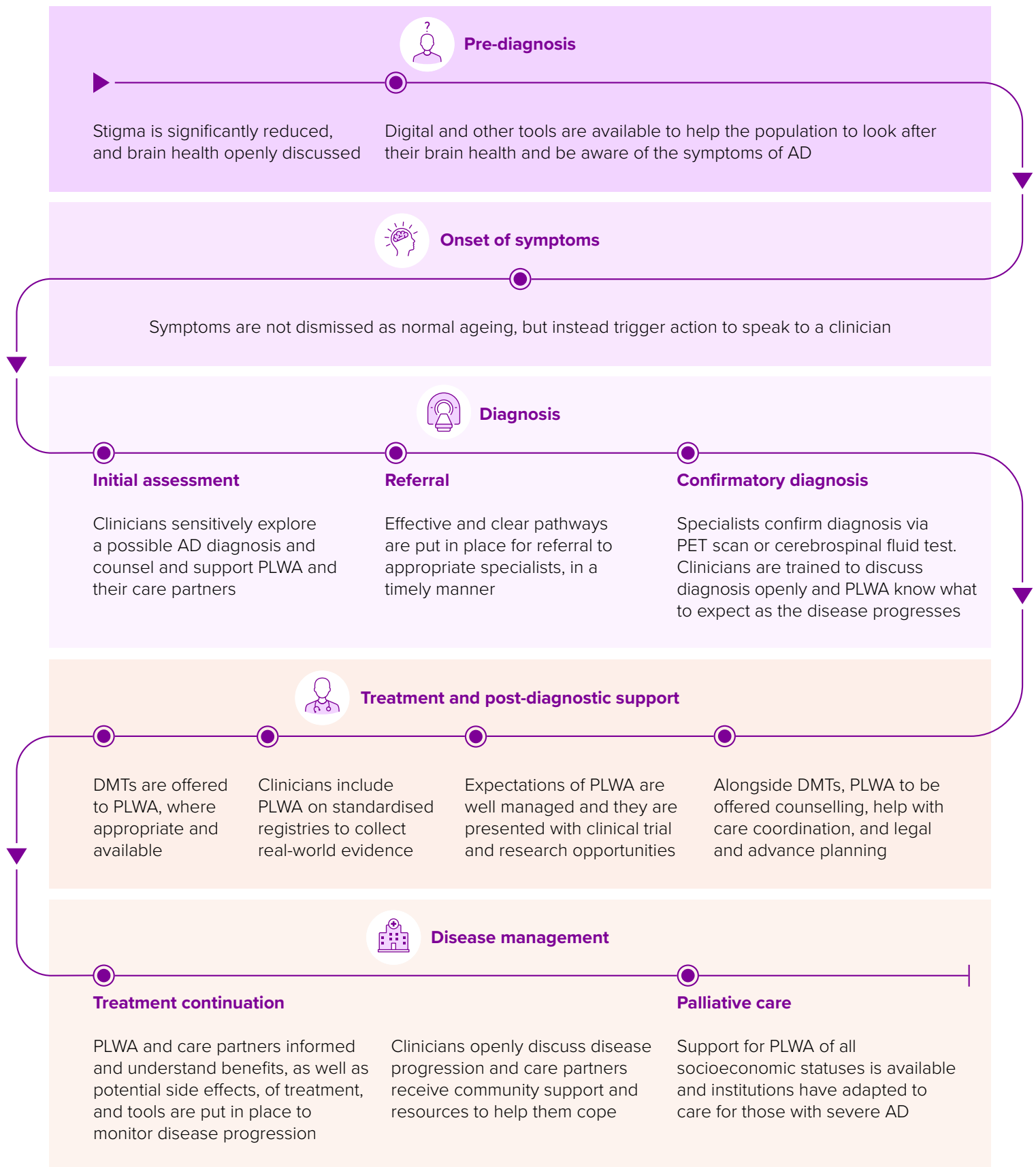


Figure 3. Optimal PLWA and care partner journey, proposed by the F.A.S.T. Council

To achieve this optimal journey, the F.A.S.T. Council took each stage of the PLWA and care partner journey and identified actions to support PLWA to navigate their journey and receive optimal care.

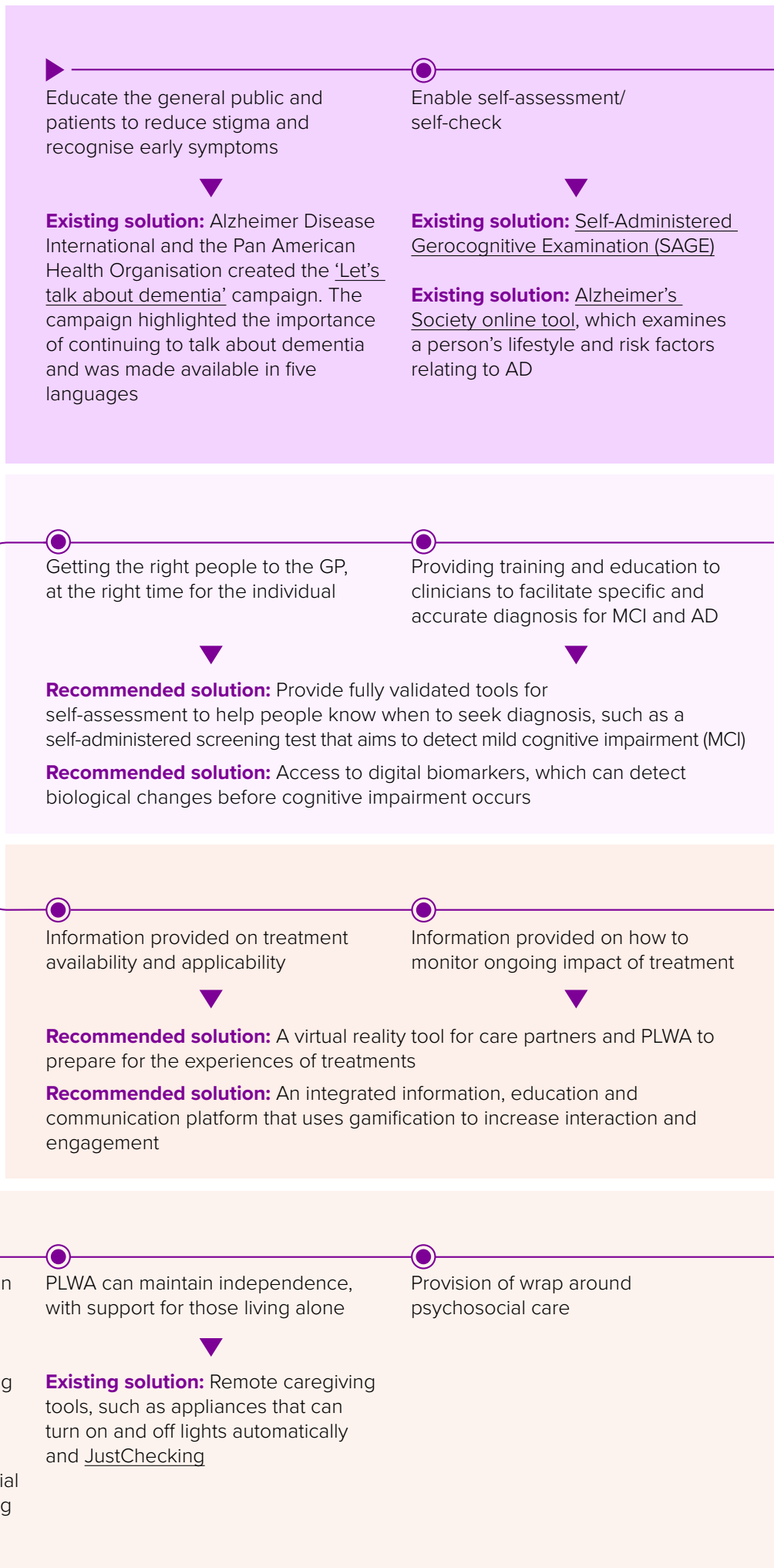


Figure 4. Actions identified by the F.A.S.T. Council that could support PLWA navigate their journey and receive optimal care.



Pre-diagnosis

Provide reassurance for the at-risk population

Recommended solution: Use digital channels to share positive messages, personal stories and encourage positive conversation

Make it easier to find support solutions when patients have neurological concerns and more easily navigate available tools

Recommended solution: Using digital tools to better support, enhance positive lifestyle and preventative behaviour

Educate GPs to recognise symptoms early and understand the benefit of referring PLWA to specialists

Existing solution: Telemedicine and virtual platforms, such as [Project ECHO](#), can help GPs gain knowledge around AD detection and diagnosis

Additional recommended solution: Share information for clinicians in an interactive and engaging way (e.g. gamification)



Diagnosis

Ensuring ongoing engagement with specialists and GPs post-diagnosis

Recommended solution: develop mobile application that can remotely track changes to ensure timely contact with clinicians

Promoting access to trusted resources following diagnosis (e.g. for lifestyle modifications)

Greater involvement of care partners in what diagnosis means



Treatment and post-diagnostic support

Treatment scheduling and consistent follow up

Consistent availability of treatments across countries

GPs aware of latest developments in treatment space



Disease management

PLWA and care partners can communicate with others in similar position

Existing solution: [AlzConnected](#), a platform for PLWA and care partners to form social connections with others in a similar position

Care partners receive training and support to help them look after PLWA

Recommended solution: Ensuring digital companion tools are AD specific and signposted to PLWA and care partners

Clinicians understand the impact of co-morbidities

Recommended solution: Using AI to join up activity monitoring tools to broader technologies and clinicians

Defining inclusive language in Alzheimer's disease

In addition to providing pathway specific solutions to enable better care to be provided to PLWA and more support to be given to care partners, the F.A.S.T. Council also identified the need to use empowering and respectful language when talking about, and to people with, AD to help break down the barriers of the stigma associated with this condition – including for those who may not be familiar with AD and its terminology, such as younger people.

A small number of F.A.S.T. Council members hosted a series of workshops with Roche's CareRing network (a global internal community for employees that are either living with a disease or have experience providing care for a particular disease), to discuss appropriate language to use with PLWA. Five key recommendations were made for the development of an AD-appropriate lexicon:

- 1. People** – using inclusive language to respect identity and sense of self
- 2. Empowerment and personhood** – using language that respects people's preferences, and highlights their strengths and abilities
- 3. Communication** – using language that supports changes in communication
- 4. Effect of AD** – using language to support changes in personal experience
- 5. Emotional journey** – using language that supports resilience and frames the positives

It is important to note that language, social and cultural differences all affect preferred terms, especially since AD is a progressive disease and experiences are highly individual. The F.A.S.T. Council made every effort to develop inclusive language that is flexible and contextually appropriate and that could be used by the AD community across the world. However, differences remain between cultures, geographies and native languages which can alter the understanding and nuance of the language used in AD. For example, in Sweden and Finland, many POs recommend moving away from the use of the term 'dementia' as a result of its negative connotations.

Further information on inclusive language can be found in the [Guidelines for the ethical and inclusive communication about/portrayal of dementia and people with dementia](#), co-authored by Alzheimer Europe and the European Working Group of People with Dementia.

Communicating on ARIA

The F.A.S.T. Council recognised that questions of lexicon and communication are particularly important in relation to possible side-effects from DMTs – both during clinical trials and when prescribed for treatment – including amyloid related imaging abnormalities (ARIA). By providing PLWA and their care partners with the right information on ARIA, they are enabled to take empowered decisions around treatment and offer informed consent. Healthcare practitioners (HCPs) at all levels should be empowered to discuss ARIA with PLWA who are receiving treatment and their care partners. A suggested process for introducing ARIA to PLWA and their care partners is outlined below, which should be considered in line with other recommendations, such as ensuring visual aids for educational activities with PLWA.

For more information on the lexicon developed, please refer to the [Appendix](#) of this report.

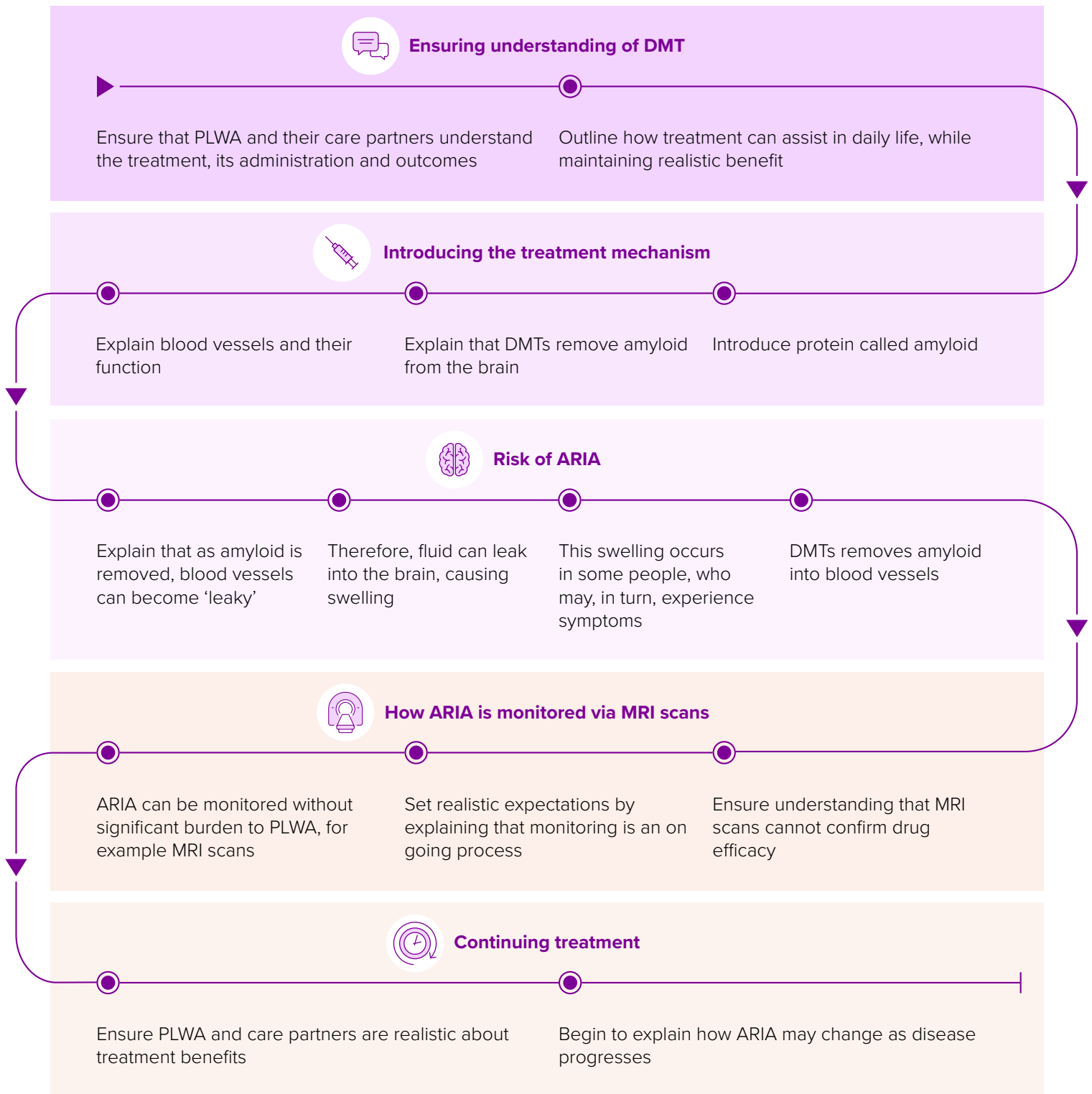


Figure 5. Process for introducing ARIA to PLWA and their care partners, proposed by the F.A.S.T. Council.

Raising awareness and advocating for better care

Raising awareness in Alzheimer's disease

While public awareness of AD is high, there is a lack of tolerance and understanding around symptoms, treatment options and the care needs of PLWA. To improve care now and in the future, stakeholders must work together to increase awareness of the holistic needs of PLWA and their care partners.

The F.A.S.T. Council identified the following areas where awareness is most needed during the first Council meeting:

- Support towards awareness and education programmes for the general public and HCPs
- Specialist training for HCPs to improve knowledge and attitudes in clinical practice
- Support tools and clear information for people living with dementia and their care partners around the world
- Knowledge sharing from those with lived experience to support destigmatisation
- Promotion of prevention strategies for good brain health, including memory screenings
- Increased awareness of the needs of care partners
- Promotion of social initiatives to create dementia friendly communities
- Ongoing collaboration in the creation of tools in AD





F.A.S.T. Council case study: Portraits of Care research

- The experience of informal caregiving can be challenging, with impacts ranging from financial hardship to impaired psychological wellbeing. At present, there is limited research exploring the care partner experience, which prevents a holistic understanding of their needs, the barriers they face and the realities of the caring role.¹⁷
- The Portraits of Care study was conceived to address this gap. The study was carried out by researchers at the University of Westminster (based in London, UK), in partnership with Alzheimer's Disease International (ADI) and Roche. Roche provided funding and, alongside ADI, contributed to the development and design of the study. Local dementia associations also helped develop the research approach, recruit care partners and communicate the research findings to key stakeholders.
- Researchers from the University of Westminster conducted in-depth qualitative interviews (using photo-elicitation) with 34 care partners from UK, US, Brazil, and South Africa to understand critical factors in coping with AD, during and after the pandemic.
- The research uncovered four care partner styles amongst the participants:
 - 1. Empaths:** used emotion-focused strategies to construct their care partner role ('put yourself in that person's shoes'). They developed strong coping skills, but needed psychosocial support and time-specific information.
 - 2. Organisers:** used problem-focused strategies and sought information and training early on ('I'm a pretty good expert now'). They developed strong narratives of organisation, advocacy and expertise.
 - 3. Non-identifiers:** managed some aspects of the care partner role but felt isolated and lacked knowledge and expertise ('do everything I can...there's nobody else'). They sought others to manage disease related support.
 - 4. Reluctants:** struggled with unwanted caring duties ('I didn't sign up for this'). They needed support in accepting their loved one's diagnosis and professional help with the day-to-day caring role.
- Overall the research findings highlighted the need for tailored user-driven support offerings that begin with the individual carer's experiences and needs. The research team hopes that this work will be used in the communication and development of findings and best practice guidelines to inform charities and policymakers about cost effective ways of tailoring support to fit individual carer circumstances globally.
- In 2022, a poster about the study design was accepted at the ADI Conference. In 2023, the researchers plan to share the study results at Alzheimer Europe and Alzheimer's Association International (AAIC) Conferences.
- The researcher team attended the 5th F.A.S.T. Council meeting and presented their findings. Members then discussed their importance and the development of this report.



F.A.S.T. Council case study: What makes you, you?: a motivational campaign to destigmatize AD

- The campaign celebrated people beyond their neurological condition, highlighting the unique qualities that make them who they are. While neurological conditions can slowly alter parts of one's identity, this campaign showcased PLWA as people that are not solely determined by their condition. By sharing inspirational stories, 'What makes you, you?' worked to tackle the stigma associated with AD and change the conversation around PLWA.
- 'What makes you, you?' – a video series celebrating three unique individuals with AD beyond their neurological condition – was published during the final week of World Alzheimer's Month in September 2022 in collaboration with Alzheimer Europe.
- The series received 297,466 viewings across Roche platforms, as well as almost 2,000 views on Alzheimer Europe's YouTube channel.

Education in Alzheimer's disease

The F.A.S.T. Council identified AD-specific education for clinicians as a priority, where cross-sectoral collaboration would add value. At present, a significant number of PLWA are living without a diagnosis. The responsibility for a diagnosis typically lies with specialist dementia services, meaning clinicians at primary care level are often ill-equipped to provide dementia-specific messaging and support, particularly around non-pharmacological interventions that can slow or prevent the onset of AD and maintain brain health.

Council members agreed that AD conferences can be a key place to support education for clinicians, as they enable them to keep up to date with important research, learn directly from experiences and 'trials and errors' of others, share best practices, and develop new skills and techniques.¹⁸

Addressing key policy challenges in Alzheimer's disease

There is an urgent need for AD to be prioritised by governments, to improve the care and support given to PLWA and their care partners as well as prepare health systems to provide access to early detection, timely diagnosis and care. The entry of disease modifying therapies will require a transformation of the AD patient and care partner pathway, which in turn will require concerted political commitment so those who are eligible for treatment are able to access it once it is approved and available.

As part of its discussions, the F.A.S.T. Council identified raising awareness with governments on the need to act on AD as a key priority for the AD community. Council members shared best practices on how to do so, including:

- Alzheimer's Disease International (ADI) gave various presentations during F.A.S.T. Council meetings, including how to leverage the findings of their [World Alzheimer's Report 2022](#) during political advocacy to focus attention on the need for improved post-diagnosis support and on how the ADI team had collaborated with other stakeholders to develop a submission for getting dementia treatments onto the [World Health Organization's Essential Medicines List](#).
- CanAge shared the approach they took to develop their [2022 Dementia Report](#) which benchmarks the progress made in each province and territory across Canada, to prepare for the rapidly growing rate of dementia that is looming on the horizon. The report also looks at Canada's National Dementia Strategy and the role the federal government has to play in stewarding, and funding, a collaborative approach to this important work across the country.

The F.A.S.T. Council also identified the following policy topics for patient organisations to focus on in AD:

- Getting dementia back on global, regional and local political and policy agendas.
- Driving the adoption and implementation of comprehensive national dementia strategies and plans.
- Engaging with governments and policymakers to drive change.
- Increasing equitable access to quality AD care for rural and remote populations.
- Addressing the costs of AD care, and enabling access to diagnostic tests and treatments.
- Defining and transforming the AD patient and care partner pathway to support better AD management and long-term care.

To deliver progress on these challenges the F.A.S.T. Council identified the need for increased engagement with government and policymakers to drive action and change in the following two priority areas:

1. Getting dementia back on global, regional and local political and policy agendas through policy advocacy, education and awareness and developing evidence and strategic positions to compel action.
2. Driving the adoption and implementation of comprehensive national dementia plans, including advocating for dedicated funding, sharing of best practices, and the creation of a narrative that addresses stigma and empowers PLWA.

The F.A.S.T. Council recommended the formation of a dedicated Policy Squad to develop a plan to move forward on these two policy priorities. Further detail on this Policy Squad can be found in the next section of this report.

F.A.S.T. Policy Squad

The Policy Squad, composed of members from the Council, initiated a project in mid 2022 to catalogue the extent of commitments to AD made by supranational organisations, within intergovernmental fora, regional governments and selected countries. The project also aimed to determine whether these commitments have been upheld and to identify drivers and barriers to success.

Roche, along with the Squad members, developed a research framework for data collection and analysis, and worked with an external vendor to support the research and analysis. Key insights from the 'Commitments Catalogue' research are as follows:

- While AD is on the global agenda, meaningful progress has been slow.
- Broadly, governments are off track to achieve the identified global policy goals.
- Measuring progress is hindered by gaps in concrete timelines, milestones and key performance indicators.
- Progress reporting is inconsistent.
- Unlocking funding continues to be a challenge as health systems face strains, but advocacy has been strong.
- National strategies and action plans are in place, but updates are infrequent.
- Strategies in high income countries are seeing more success in turning commitment into action.
- Multi-sectoral partnerships are supporting the operationalisation of national strategies.

The full research and findings were presented to the broader Council for awareness and to inform strategies and actions.

In 2023, the Squad held a brainstorming session to discuss the policy needs of advocacy organisations working in AD in light of the recent developments in the field. The Squad made the following recommendations for potential policy projects:

- Refine the messaging used by POs for governments and policymakers related to AD.
- Develop a tool that could guide a PO through a series of questions to help generate a set of recommended policy asks in key areas, such as early detection and the personal role in risk reduction, access to a definitive diagnosis and therapies, and late stage and care partner experience.
- Develop clear, actionable policy asks:
 - Policy ask related to driving a government funding commitment for AD, and tailored and indexed to a country's GDP and ageing demographic (i.e. population over 65 years old):
 - 'Government X invests X% of GDP to AD.'
 - Policy ask related to increasing access to a timely, accurate diagnosis of AD:
 - 'Government guarantees a person with AD is able to get a diagnosis of their disease within X months.'
 - 'Government guarantees a person with AD is able to receive a confirmatory (biomarker) diagnosis of their disease within x months.'
- Benchmark and track progress of government action on AD, through for example:
 - [CanAge Dementia Report \(2022\)](#), which assesses Canada's level of preparedness to support the projected increased numbers of PLWA in the future. The report calls for investment to increase the numbers of geriatricians per person who is 65+ and for Canadian provinces to develop clear dementia strategies, action plans or care pathways for those living with dementia.
 - Alzheimer Europe Dementia Monitor (2023 report in development), which assesses and ranks readiness across 10 areas (services, affordability, availability of clinical trials, human rights, legal, etc.). Alzheimer Europe Dementia Monitor's 2020 report [can be found here](#).
- Develop a clear narrative about the impact of access to new therapies for PLWA and their care partners, including key messages on the value of access to new medicines that personalises the value for the individual who may be eligible for approved treatments.
- Leverage the 'Portraits of Care' research project results to develop tailored policy ask(s) specific to dementia care partners.

The role industry and other stakeholders can play in supporting POs in driving policy change

The F.A.S.T. Policy Squad concluded that policy changes in AD must take a system-wide approach, and be done through collaboration of stakeholders, including governments, policymakers, advocacy organisations, PLWA and their care partners, clinicians, researchers and industry.

The pharmaceutical industry can help elevate and amplify the PLWA perspective in policy debates through:

- Collaborating and co-creating new evidence and tools that can be used by the AD community in policy advocacy.
- Partnering with the AD community to mobilise and advance a set of shared policy priorities and policy asks.
- Amplifying and supporting the AD community in their policy and political advocacy efforts
- Being an active contributor to AD policy debates.
- Building the case for greater action and collaboration by providing data and insights on the scale of the problem as through the development of solutions.
- POs primary role would be to disseminate information and facilitate education of constituents about study outcomes.

POs can also help elevate and amplify the PLWA perspective in policy debates through:

- POs with national reach would be well-placed to communicate results in their specific context and facilitate local or national advisory boards with key stakeholders to better understand the implications of the results.
- POs with international reach felt that they had a duty to disseminate information to national member organisations and provide constituents with the opportunity for direct discussion with the company leading the clinical trial.



Conducting inclusive clinical trials

Recruitment for, and participation in, AD clinical trials has historically been a challenge.^{19,20} Several barriers to trial participation have been identified via peer reviewed papers; insights gathered by the F.A.S.T. Council from PLWA and their study partners before, during and after clinical trials; clinicians involved in trial management and from local POs.^{16,17} These barriers include:

- Lack of a study partner to support the PLWA throughout the trial and to note cognitive changes or treatment effectiveness.
- The pain and fear associated with undergoing invasive procedures during a trial.
- Distance to the trial centre and travel costs.
- Time commitment necessary from both the PLWA and their study partner.
- Concern of the risks to which PLWA may be exposed.
- PLWA's comorbidities.
- The historical lack of positive effects in AD clinical trials.
- The lack of ability to engage with underrepresented populations.
- Lack of health professionals' training about inclusive clinical trials.
- Unavailability of care partners due to time limits.

Once these barriers were identified, the Council held an in-depth discussion on a few of these issues including how best to communicate clinical trial results, defining roles for the pharmaceutical industry and for POs. The following recommendations were agreed upon:

- Facilitate in-depth conversations on clinical trial results with stakeholders across the entire AD community (e.g. industry experts, POs and key opinion leaders).
- Ensure the trial results are translated with participant inclusivity in mind.
- Consider country-specific or demographic preferences for information uptake, particularly relating to information available digitally.
- Provide educational resources in lay language that address key questions (e.g. are the results positive?; who is the target group of the trial?; what is the cost of treatment?).

The Council then made a set of recommendations on how to conduct clinical trials, details on which can be found in the case study below.

F.A.S.T. Council case study: **Clinical trials report and playbook**



- Recognising that AD clinical trials can only be successful if they fully embrace meeting the needs of PLWA and their study partners, the Council developed a playbook and a report on Integrating the perspectives of people living with Alzheimer's disease and their study partners into clinical trial development, which included input from PLWA, study partners and POs.
- These resources were launched during the Alzheimer Europe Conference in October 2022 and published online for use by the AD community.
- They include detailed recommendations on how to design a clinical trial to take into account the needs of PLWA and their study partners before, during and after participating in a clinical trial.

Diversity and Inclusion with Alzheimer's disease

During F.A.S.T. Council meetings and discussions, the importance of diversity, equity, and inclusion (DE&I) in AD clinical trials was repeatedly identified. The burden of dementia falls disproportionately on certain groups across societies. For example, AD has a disproportionate impact on women compared to men, and on marginalised communities who are at greater risk of developing AD. The Council recognised that only by countering these issues can progress be made in AD.

F.A.S.T. Council case study: Ensuring DE&I in AD clinical trials

- The F.A.S.T. Council integrated DE&I at key points throughout its activities, including during their 4th meeting. Recognising that DE&I is especially crucial in AD research, Roche are supporting the development of a dedicated report on DE&I. The report has been developed in collaboration with F.A.S.T. Council members as well as academic and clinical experts. The report is due to be published in Q4 2023.



Conclusion

Collaboration between the pharmaceutical industry and patient organisations (POs) in Alzheimer's disease (AD) is critical to progressing towards a future in which people living with AD (PLWA) are treated with respect and can live fulfilling lives with their disease managed well.

This report outlines how collaboration can be set up and managed to benefit all parties, the areas in which collaboration is most needed, and how outputs can be co-created to influence change at local, regional, national and international levels.

The Finding Alzheimer's Solutions Together (F.A.S.T.) Council is committed to supporting the journey of PLWA, their care partners and families, and believes that together, the AD community can help improve outcomes and provide better quality, patient-focused care and research. We hope this report and the wider work undertaken by the F.A.S.T. Council can act as a blueprint to pave the way for meaningful collaboration that works to improve outcomes for PLWA and their care partners.



Glossary

Alzheimer's disease (AD): Alzheimer's disease affects the brain through a build-up of abnormal proteins called 'plaques' and 'tangles', which disrupt nerve cell functions and, over time, cause nerve cells to die.²¹ The build-up of these proteins begins up to 20 years before symptoms emerge.²² AD is the most common cause of dementia.²³ Dementia describes a set of symptoms that impact on function (activities of daily living), and may include memory loss and difficulties with thinking, problem-solving or language. AD is progressive, which means the symptoms gradually get worse over time, with the clinical presentation and severity varying from person to person.

Amyloid related imaging abnormalities (ARIA): ARIA represent a variety of imaging features identified in patients with AD being treated with amyloid lowering therapies (for example, a disease modifying therapy). While patients either have or do not have ARIA, some patients will experience symptoms as a result.²⁴

Care partner: Family member, friend or paid helper who regularly looks after someone with a condition.²⁵

CareRing: CareRing is a global Roche internal community for employees that are living with a disease or are themselves carers. CareRing is designed to create a safe and trustful space for employees to connect, share experiences and provide support to each other.²⁶

Disease modifying therapies (DMTs): A disease modifying therapy or a disease modifying treatment slows the progress of AD. In contrast, symptomatic treatments only help alleviate symptoms. No DMTs are currently licenced for AD, but research is ongoing.²⁷

Finding Alzheimer's Solutions Together Council (F.A.S.T. Council): A bi-annual council where AD patient organisations and Roche discuss areas of collaboration and work together to understand the perspectives and needs of AD. The organisation and funding of the Council is led by Roche.²⁶

Mild cognitive impairment (MCI): A condition in which someone has minor problems with cognition – their mental abilities such as memory or thinking. In MCI these difficulties are worse than would normally be expected for a healthy person of their age. However, the symptoms are not severe enough to interfere significantly with daily life, and so are not defined as dementia.²⁸

People living with Alzheimer's disease (PLWA): Someone who has been diagnosed with AD.

Photo elicitation: Photo elicitation is using photographs or other visual mediums in an interview to generate verbal discussion to create data and knowledge. Different layers of meaning can be discovered as this method evokes deep emotion, memories and ideas.²⁹

Professional study partner: Someone, usually a paid healthcare professional or auxiliary clinician, who is involved in supporting the PLWA with their treatment monitoring and trial participation.³⁰

Study partner: Someone who is directly involved in supporting PLWA with their treatment monitoring and trial participation. This role can be undertaken by a family member or a friend.²¹

Resources

Alzheimer's Disease International. World Alzheimer's Report 2022 – Life after diagnosis: Navigating treatment, care and support. 2022. [Available here](#) [Last accessed July 2023]

Alzheimer Europe. Dementia as a European Priority – A Policy Overview. 2020. [Available here](#) [Last accessed July 2023]

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F.A.S.T. Council. Integrating the perspectives of people living with Alzheimer's disease and their study partners into clinical trial development. 2022. [Available here](#) [Last accessed July 2023]

Gove, D. et al. The challenges of achieving timely diagnosis and culturally appropriate care of people with dementia from minority ethnic groups in Europe. *International Journal of Geriatric Psychiatry*. 2021. [Available here](#) [Last accessed July 2023]

Appendix

Additional detail on the AD-appropriate lexicon to use can be found below.

People



Inclusive language to respect identity and sense of self

Suggested language

- Person/people with AD
- Study partner
- Care partner
- Person/people affected by AD

Guidance on phrases to avoid

- Caregiver
- Patient
- Service user

Include 'Getting to know you' questions

- 'How are you doing?'
- 'What challenges are you having?'
- 'What is important to you?'
- 'How do you like to be supported?'

Key findings

- Wherever possible, use the **person's name** or **'you'**
- Recognise that people have a life outside of AD – **personalities, stories** and **co-morbidities** need considering to find out what is important to each person living with Alzheimer's disease (PLWA)
- Asking questions is critical to **determine what support the PLWA needs**
- **Motivational interviewing** techniques can be used to better understand factors outside of Alzheimer's disease (AD), such as the persons beliefs, feelings, and the care they want
- Guidance on language should be considered alongside other factors, such as language, social, and cultural differences, which can all affect preferred terms. As such, lexicon needs to be contextually appropriate (for example, considering the language user's relationship to the PLWA) and **flexible to individuals** and their preferences

Empowerment and personhood



Language that respects people's preferences, and enforces their strengths and abilities

Suggested language

- Working with...
- Has the right to...
- Support a person with...

Guidance on phrases to avoid

- Doing to...
- Allowed to...
- Administered to them...

Include 'Getting to know you' questions

- 'What is important to you?'
- 'Do you have someone who could give you more support?'
- 'Who do you contact for....?'
- 'Is there someone who helps you with tasks, such as shopping?'
- 'Is there someone you socialise with often?'

Focus on asking for permission and telling someone's story in their own words

Key findings

- Focusing on abstract concepts such as 'autonomy' or 'empowerment' does, in general, not allow PLWA to relate to language – instead, more focus should be put on respecting individuals, their thoughts, hearing their voice, and nurturing their **involvement** and **inclusion**
- Where possible, use tools (such as sticky notes, digital apps and other non-pharmacological interventions) to help PLWA **keep independence** for as long as possible
- Seek to facilitate conversations with PLWA to figure out **what is important to them**, the help they want, and how they would like to receive support
- Ask questions to help them to identify who their study and / or care partner may be. Seek to **normalise the need for support**, and explain that this is not unusual or disempowering
- There is a need to **train healthcare professionals (HCPs) on inclusive language**, as well as encourage them to develop a relationship with the PLWA and their care partners to be able to provide holistic care

Communication



Language that supports changes in communication

Suggested language

- 'Reaction to fear, frustration and pain'
- Multi-modal communication (pictures, video, animation)

Guidance on phrases to avoid

- 'Challenging behaviours'
- 'Expression of unmet need'
- Complex wording and medical jargon

Highlight that AD is non-discriminatory, it can affect anyone and all ages

Key findings

- The use of complex words increases the distance between PLWA and care partners and HCPs
- Language should support emotional connections and ensure PLWA feels safe and comfortable
- **Multi-modal** and **non-verbal communication** is important – for example, pointing to images of feelings can allow PLWA to express themselves
- Bear in mind that space should be given to **allow PWLA to adapt**, and for **language to change** over time as the needs of the PLWA change (which could be from day-to-day)
- Focus on the positives, and what the person **can do** – it is possible to live well with AD despite facing some problems – and try to highlight solutions to specific problems
- **HCPs' own beliefs and language** can add to the **stigma** associated with AD, and consequently affect their delivery of solutions
- There is a need to ensure resources are available on consent and decision making. These should be contextual, since, for example, cultures with more community-based decision making may face unique issues

Effect of AD



Supporting changes in personal experiences with language

Suggested language

- Effect of AD
- Reason AD may cause change
- Challenges of AD

Guidance on phrases to avoid

- Impact of AD
- Burden of AD

Key findings

- Avoid using 'unpaid care' to refer to the care provided by care partners
- Avoid language that could suggest that PLWA is a 'problem' and that their care partner is 'having to look after them'
- Using **exercises as a way to maintain memory** is useful, and can positively reinforce the effort of the PLWA
- Important for care and/or **treatment partners to have the information** they need about the support and tasks they are going to take on in order to feel prepared
- Allow **time for treatment partner and PLWA to adapt**, since living with AD is a continual process of change

Emotional journey



Language that supports resilience and empowerment

Suggested language

- Anxiety and depression
- Coping with stress
- Building resilience

Guidance on phrases to avoid

- Hopelessness
- Negative framing

In recognition of the emotional journey for care partners, it may be appropriate to use 'anxiety and depression'. However, it is often more appropriate to use 'coping with stress' or 'building resilience' when in conversation with PLWA to focus on the positives

Key findings

- There is a need to recognise the **different journeys** of care partners and PLWA – within these journeys, their needs are different, and therefore so is the language
- It is important to recognise that AD gets worse over time – attention span can reduce, can **lose language capacity** and develop aphasia (loss of ability to understand or express speech) – it is important to prepare PLWA accordingly
- Focus on building on areas that PLWA and care and/or treatment partners can **control**
- Help PLWA and care and/or treatments partners recognise that emotions are normal; **acceptance and commitment** are key terms around this
- **Positive framing** and supporting resilience are important
- Care and treatment partners can experience mental health difficulties, need to recognise this and be able to use 'anxiety' and 'depression' terms in this context
- **Position AD like other conditions** (such as diabetes), that happen and are treated – this can be helpful for PLWA and treatment partners

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