

Shared Wisdom, Real Impact

The Knowledge is Power Report

Key Findings

June 2026



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About Knowledge is Power

Knowledge is Power began in Wales.

It was developed from research at Bangor University about what helps people living with dementia to be resilient after the diagnosis. In that research, people with dementia and their carers used the phrase “knowledge is power” to describe how learning about living with dementia was important for their resilience.

People with dementia, carers, and supporters worked together across three DEEP groups — Caban Bangor University Educators, DEEP United Dwyfor & Meirionnydd, and Fuse and Muse in Swansea.

Their goal was to create a practical booklet that was easy to read and easy to use. Most importantly, it had to be written by the people who live with dementia every day.

The content comes from real experience. The tone is honest but also carries a message of hope

KNOWLEDGE IS POWER

WALES

Handy hints that might help make life a little easier after a diagnosis of dementia

“Dementia is life changing, but it’s not life ending. Take advantage of every opportunity offered to you. You must learn to ask for help, because nobody should be going through this on their own”.



This booklet was written by people living with dementia, for people living with dementia. It includes information and advice that we hope you may also find useful.

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GRYM MEWN GWYBODAETH

CYMRU

Awgrymiadau defnyddiol a allai helpu gwneud bywyd ychydig yn haws ar ôl cael diagnosis o ddementia.

“Mae dementia yn newid eich bywyd, ond nid yw’n diwedd ar fywyd. Manteisiwch ar bob cyfle a gewch chi. Mae’n rhaid dysgu gofyn am help, oherwydd ni ddylai neb fynd trwy hyn ar ei ben ei hun”.



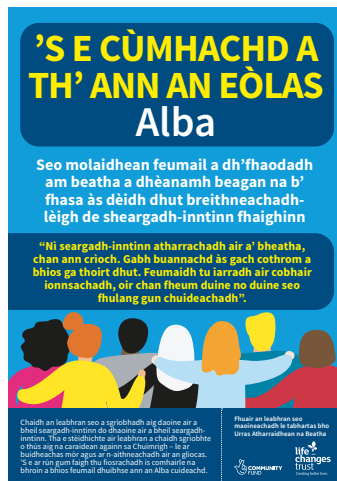
Ysgrifennwyd y llyfryn yma gan bobl sy’n byw gyda dementia, ar gyfer pobl sy’n byw gyda dementia. Mae’n cynnwys gwybodaeth a chynghor y gobeithiwn bydd yn ddefnyddiol i chi.

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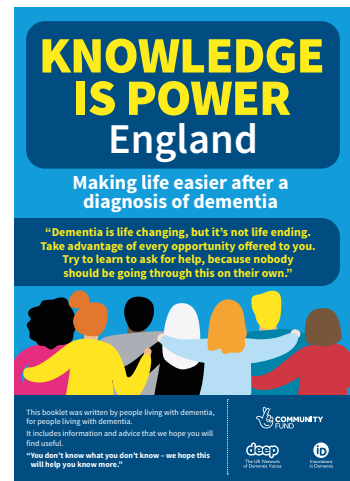
After the Welsh version came editions in Scotland and England, a Carers version, and Knowledge is Power 2, which focuses on everyday life.



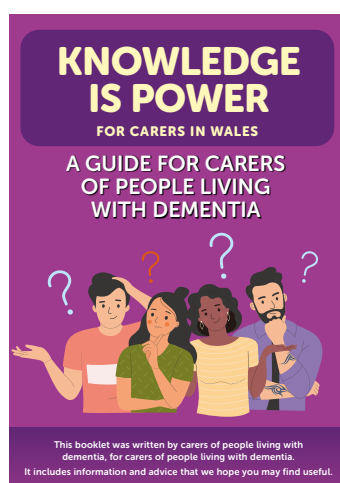
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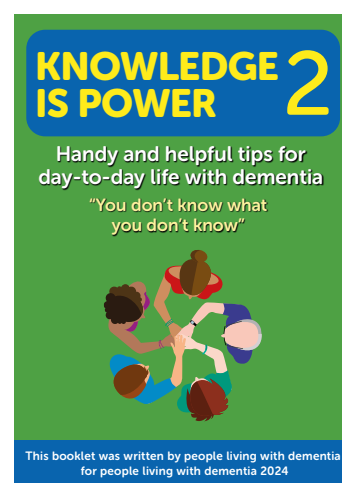
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This growth shows the strength of the DEEP network. DEEP is run by Innovations in Dementia CIC and brings together more than 80 peer groups across the UK. These groups are led by people with dementia who meet, speak up, share ideas, and influence change. The spread of Knowledge is Power happened because people with dementia inspired each other, supported each other, and shared what worked.

Across Wales over 18,000 copies of Knowledge is Power have been requested and distributed around professional organisations and people with dementia and carers. A further 13,000+ commissioned and funded by external service providers. In England over 10,000 copies have been distributed.

Co-creation is central to Knowledge is Power. It is a way of working that shares decisions, shares power, and values people's lived experience. When people with dementia help shape the words, layout, and priorities, the finished resource is clearer, more relevant, and more authentic.

It also sends a strong message: people with dementia have a lot to offer, a lot to say, and we are all the wiser for listening.

Acknowledgements

We'd like to thank the project advisory group, namely:



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Jayne Roberts

About this evaluation

People have always told us how much they valued Knowledge is Power. However, we lacked more detailed insight into how it has been used, and most importantly, what difference it has made in people's lives.

With the generous support of the Hallmark Foundation we set about finding out.

We wanted the evaluation of Knowledge is Power to follow the same values. We formed a mixed team: seven people with dementia, one carer, two Bangor University academics, and a Director from Innovations in Dementia.

All experts-by-experience in the team were involved in the development of Knowledge is Power in Wales and England. Together we agreed the aims of the evaluation, designed the evaluation strategy, designed the survey questions and design, and analyzed the results.

The survey ran in English and Welsh for six weeks in late 2025 and was completed by 100 people. It focused on what matters most to readers: the clarity and relevance of the information, the logistics of actually getting hold of the booklets, and the real-life impact.

This report shares what we learned.

About this report

This report describes what people think about Knowledge is Power.

The aim is to help a wider audience understand what people told us, why it matters, and what we can learn from it.

You can find a full description of the results, question by question, together with our thoughts on specific implications for practice in the version of the report with full appendix published separately.



Who took part in the survey?

One hundred people responded to the survey. They came from all sorts of backgrounds. Most were professionals—people working day to day with individuals and families living with dementia. But we also heard from carers, volunteers, and importantly, people who are living with dementia themselves.

Most respondents were between 55 and 64 years old, most were women, and almost all identified as White. People lived in different parts of the UK.

What this tells us

Hearing mainly from people already connected to services and dementia support is a strength. But we must also keep working to reach people who are less represented: younger carers, families from minority ethnic backgrounds, and those who may not yet be accessing support.

How people use Knowledge is Power

People told us they use the booklet in all sorts of ways. Some read it right after diagnosis, when everything feels raw and confusing. Others use it later, dipping in and out as they need it. Professionals said they use it during appointments, group sessions, or when they are out in the community. Carers often shared it with family members to help them understand what a diagnosis means.

What this tells us

Something we heard again and again is that printed copies matter. For many people, reading something physical makes a real difference.

Most copies went to carers, people with dementia and family members, but it also reached a wider audience through community networks and events—showing its value for both direct care and wider awareness.

What professionals think of Knowledge is Power

Some quotes from professionals:

“Absolutely BRILLIANT booklets full of valuable information and advice that can give people a lot of peace of mind... It can be a very lonely journey for families, but these booklets give hope and show people that support and advice are available.”

“It is the best resource that we hand out. It contains all useful information in one place instead of people having various leaflets which can be very overwhelming.”

Professionals were very positive. Many told us the booklet is clear, practical and warm. They especially appreciated the tone which they described as friendly, human, and not overwhelming.

Several said it was the best resource they had used in years.

Has it affected the way they support people?

Seven out of ten professionals said Knowledge is Power changed the way they support people. For some, it helped them give clearer explanations. For others, it made conversations feel kinder and more grounded in real experience. Some told us that having everything in one place helped them feel more confident too.

“It is a resource that we can hand out as soon as we meet new people affected by dementia... a great ‘go to’ guide.” **Professional**

What this tells us

Clear, simple language and a straightforward layout makes a big difference.

Their bright, positive design and bilingual options help reach more people.

Bringing everything together in one place saves time and reassures people that they have what they need to know.

Beyond practical help, the booklets offer confidence and hope. They make dementia feel less daunting and show that support is available.

Co-production with people living with dementia adds authenticity and trust.

What people with dementia and carers think about Knowledge is Power



“Having copies of the KiP book helped me to feel more in control of my life, as I could offer a copy to people who just ‘did not get’ dementia and ask them to read it. It felt empowering!” **Person with dementia**

“It helps me take back some control of the situation” **Carer**

(it helps me feel) “Supported and not alone, to understand where to go for what I need, educational, a comforter.....” **Person with dementia**

Having asked professionals what they thought, we asked the same questions to people with dementia and carers.

Then we compared this with what people with dementia actually told us.

The views matched very closely. The only difference was emphasis: professionals focused more on clarity, while people with dementia spoke more about emotional reassurance.

People living with dementia said the booklet helps them feel less alone. They said it gives them hope and helps them understand what support is out there. Carers described it as something they return to again and again, especially during difficult moments.

Different versions of the booklet

No matter which version people read—the Wales version, the England version, the Carers edition, or Knowledge is Power 2—the message was similar. People found the booklets helpful, approachable and relevant.

Across all versions of Knowledge is Power, people were very positive about the individual sections covering different topics. Whether they read the Wales edition, the England edition, the Carers booklet, or Knowledge is Power 2, the message was the same: most sections were clear, useful, and relevant.

Readers said that the booklets made sense, were practical to use, and helped them understand what support is available. In every version, large numbers of people marked whole sections as “helpful,” and it was rare for anyone to say a section was not useful.

In the Wales edition, almost every section received strong support. Sections such as ‘From us to you’, ‘Benefits and Allowances’, ‘Travel and Mobility’, and ‘Support you may come across’ were rated as helpful by everyone who commented. Other sections, including support for accessing services, discounts, legal considerations and places to find help, were also valued. Even when a section was not directly relevant to someone’s situation, people still said it was good to have the information there.

The England edition showed the same pattern. Sections on benefits, practical resources, and support options were rated as universally helpful. Readers also valued the sections on myths about dementia, personal messages, and recommended reading. Only a few areas—such as going out, mobility aids, future planning and blogs by people with dementia—were rated as less relevant, and even then only by a very small number of people.

The Carers edition also received strong feedback. Carers particularly valued information on organisations that can help them, how to work with health and social care professionals, legal and money matters, and what to do after a diagnosis. Topics such as day-to-day living, mental health and well-being, and rare dementias drew more mixed responses—mainly because not every caring situation is the same.

Finally, Knowledge is Power 2, which focuses on day-to-day life after a diagnosis of dementia, was described as widely useful and practical. Most readers found the sections helpful, with very few marking anything as “not helpful.”

What this tells us

These findings show that the structure and range of topics in all four versions of Knowledge is Power are working well. People appreciate information that is clear, practical and directly connected to real-life situations.

The consistently strong ratings across almost every section suggest that the breadth of content is a strength rather than something that overwhelms readers.

People value being able to dip in and out of different parts of the booklet depending on what they need at a particular moment.

“This booklet is REALLY helpful, especially when info & advice given in person is quickly forgotten, and this is a permanent record they can share with a friend, partner, son or daughter.” **Person with dementia**

“The booklet is a nice size and can be referred back to any time — when the time is right for them.” **Carer**

For practice, this means keeping the variety of sections, because readers use the booklet in flexible and very personal ways.

It also means holding on to the balance between emotional reassurance and practical guidance, as both are important to people at different points.

Some topics will only matter to certain readers. However, their inclusion still matters because they may be exactly what one person needs at a crucial time.

Future updates should continue to use simple language, clear layout, and examples that feel real and relatable.



Does co-production matter to the readers?

“I feel more confident sharing it with those with a diagnosis because it was created by their peers.” **Professional**

“I think that it is an excellent resource... Knowing that it has been devised in collaboration with people living with dementia, carers and professionals gives me the confidence to share it with our members – knowing that all aspects are covered and I’m handing out a booklet that WILL HELP!” **Professional**

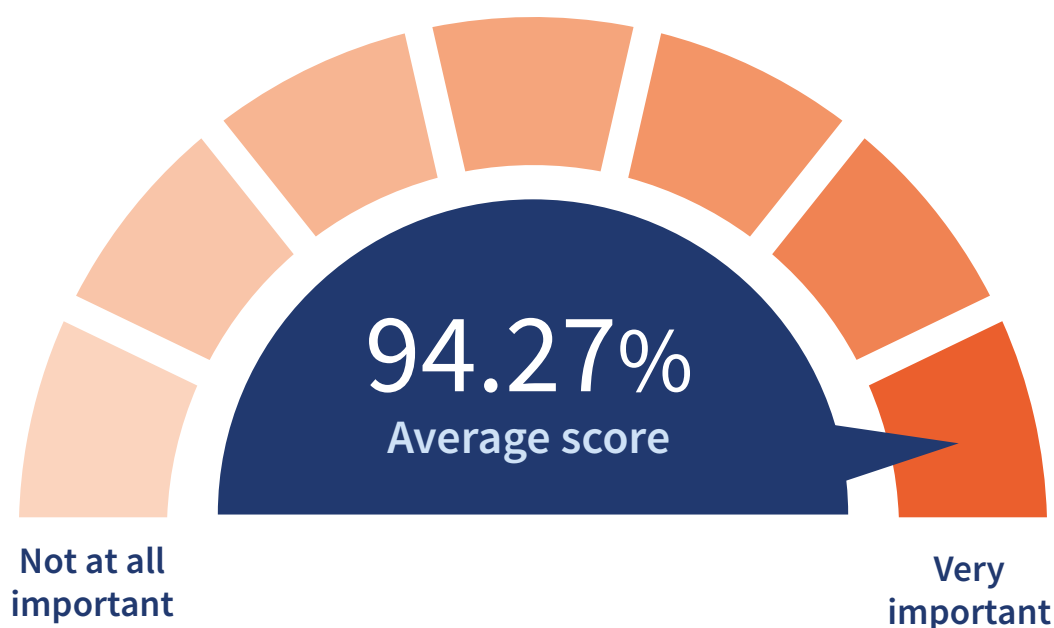
“Hearing practically from those living with a dementia and dealing with the challenges daily, results in a far more relevant guide” **Person with dementia**

We believe that co-production matters because it means that what we produce reflects real experiences and priorities.

When people with dementia and carers lead the creation of materials, it challenges stereotypes, builds trust, and promotes empowerment. It signals that people with dementia are not passive recipients but can be active contributors with valuable insights.

...but was this view shared by readers?

We asked people to score from 0 (not important at all) to 100 (very important). The average rating was 94.27 out of 100. This strikingly high score shows that people deeply value resources created by those with lived experience.



Respondents highlighted that knowing guidance comes from individuals who truly understand dementia fosters confidence and emotional connection. It changes perceptions by demonstrating capability and resilience, making advice more practical and empathetic.

What this tells us

We should always put co-production at the heart of any resource we create. That means involving people with dementia and carers at every stage, from the earliest ideas right through to the final version.

It also means being clear that lived experience is a form of expertise.

When we recognise and value this, we strengthen people's confidence, promote inclusion, and ensure that the final resource truly reflects the realities of those who use it.



What did people do after reading the booklet?

It is one thing for a resource to be informative, but real value comes when it helps people take action.

People told us that the booklet did far more than simply offer information. It gave them the confidence to act.

“...it has given us direction and support, the courage to attend groups and zoom meetings, getting to know others and how they cope with how to deal with Dementia” **Person with dementia**

Many readers shared the resource with others, which was the most common response. A high percentage of respondents also contacted services, made changes at home, applied for benefits, or began sorting out legal or financial plans.

These actions show that the booklet helped make complicated processes feel more manageable. Several people said it helped them feel less alone and more informed, which encouraged them to take the next step—whether that was reaching out for support or making practical adjustments in their daily routines.

What this tells us

These findings show that resources like Knowledge is Power work best when they not only explain things but also help and inspire people take meaningful action.

Clear guidance on financial planning, benefits, and how to contact services is especially valued. Keeping these parts easy to find and easy to follow will strengthen the booklet even more.

The results also show where extra support might help. Some people felt less confident about taking social steps, such as joining groups or building new connections.

Providing simple examples, gentle encouragement, or stories from others who have taken these steps could help people feel less anxious and more supported. Above all, the findings highlight the importance of practical, co-produced information that helps people move from “knowing” to “doing” in ways that feel manageable, hopeful, and empowering.

Getting hold of Knowledge is Power

We asked people how they first heard about Knowledge is Power and who actually gave it to them. This matters because good information only helps when it reaches people at the right time and in the right way.

People told us they discovered the booklet in many different ways.

Some first saw it through health and social care professionals, memory cafés, or dementia groups. Others found it through Bangor University, training sessions, or community organisations. Others received it from friends, colleagues, group leaders, or through the DEEP network.

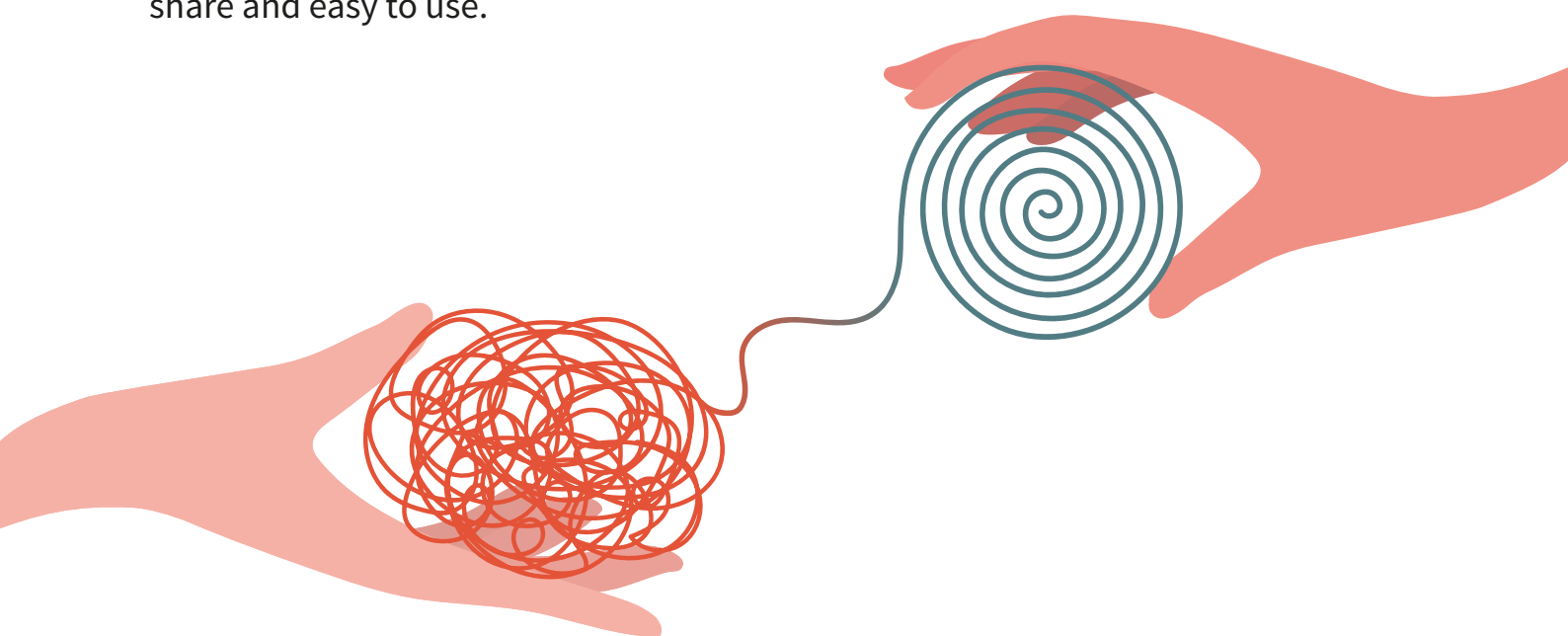
This mix of formal and informal routes shows that the booklet spreads best when many different people and organisations are involved. It also shows the importance of personal recommendation: people trust information that comes from someone they already know.

What does this tell us?

Getting Knowledge is Power into people's hands depends on strong relationships and a wide network.

Keep close links with community groups, academic partners, dementia organisations and frontline professionals

At the same time, we should continue to value word-of-mouth sharing, because people often act on advice that comes from peers. Using these varied approaches is the best way to make sure Knowledge is Power remains easy to find, easy to share and easy to use.



When is the right time to be given Knowledge is Power?

We wanted to understand not only whether people received Knowledge is Power, but whether they received it at the right time.

Timing matters. Information only makes a difference when it arrives at a point when people can use it.

If it comes too late, after important decisions have already been made or when someone is overwhelmed, its impact might be limited.

If it comes too early, people may not be ready to take it in.

Knowing when people actually received the booklet, and when they feel they should have received it helps us understand how well current systems are working.

People told us that, in many cases, they did receive the booklet at the right time. Some were given it when joining a group or starting a caring role, and others received it early in their contact with services.

However, a significant number said they got it too late, or that they wished they had known about it earlier—especially at the point of diagnosis, or even during the period of uncertainty before diagnosis.

Many described diagnosis as a moment when they felt “left in the dark,” and said the booklet would have helped straight away. Several also told us that people may need the booklet more than once, as their needs and feelings change over time.

What this tells us

These findings show that early and proactive sharing of the booklet makes a real difference.

We need to make sure it is routinely offered at diagnosis

...and again during early support sessions, memory clinic appointments, GP visits and included in group welcome packs.

This will help ensure no one misses timely support.

Just as importantly, people should be able to access the booklet again later, when they feel ready.

A flexible approach will help people get the right information when it can genuinely help them most.

Is Anything Missing from Knowledge is Power?

We asked people whether they felt anything was missing from Knowledge is Power.

Most people told us the booklet felt complete and said there was nothing missing. This is a strong sign that the core content meets a wide range of needs.

However, some helpful suggestions did emerge.

Carers, in particular, wanted more guidance aimed at them — such as clearer information about carer assessments, emotional wellbeing, and the everyday challenges of caring.

A number of people also said it would help to have better signposting to local support, including community groups, DEEP networks, and ways to find services nearby.

A few respondents felt the early stages of dementia, including the time before diagnosis, needed more attention. Others suggested adding more practical advice around legal matters, planning ahead, and explaining dementia to younger family members.

What this tells us

These suggestions show that while the booklet is already strong, adding more targeted support — especially for carers, early-stage guidance, and local signposting — could make it even more useful.



What does this tell us about resilience?

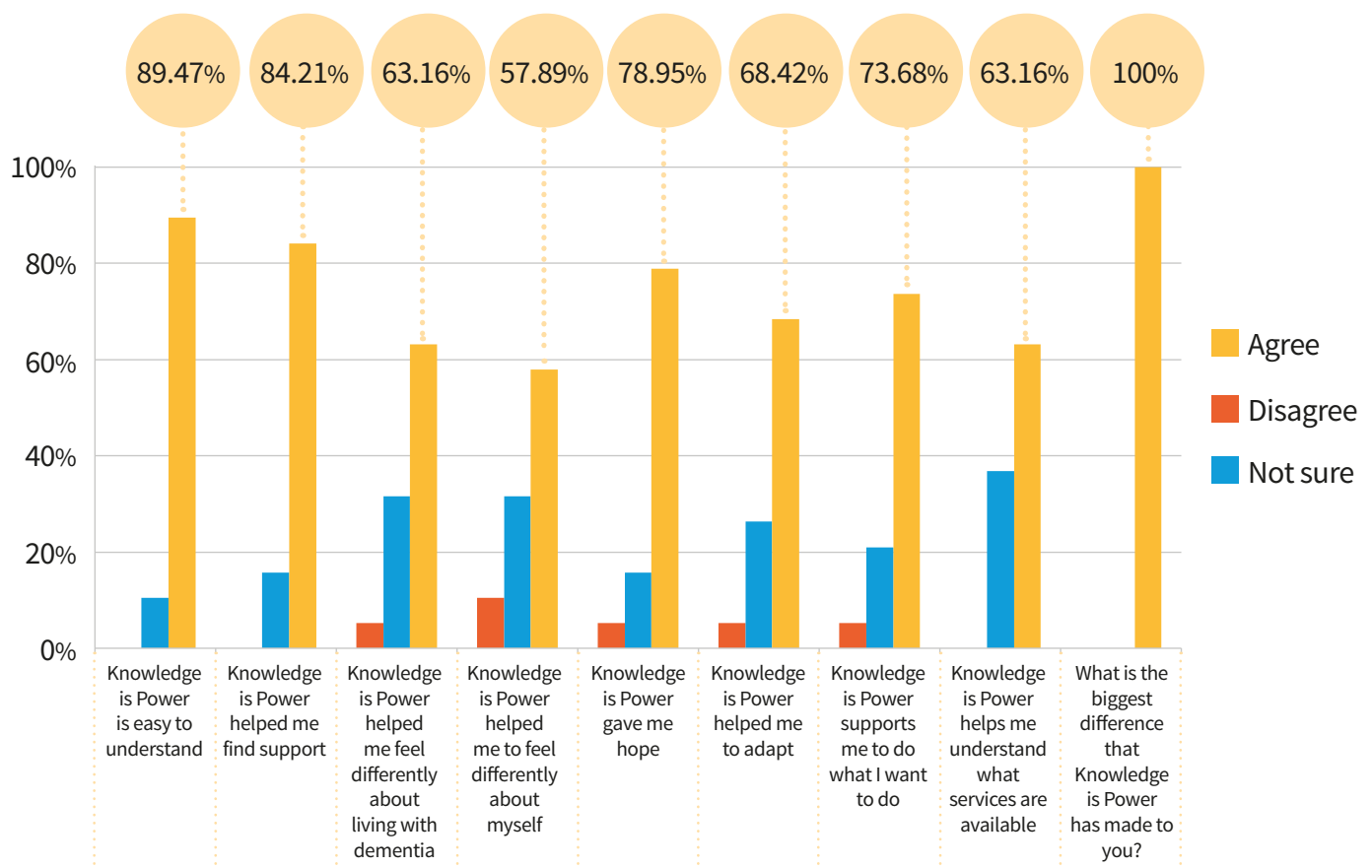
The idea for **Knowledge is Power** came from research about **resilience**—which means how people manage and stay strong when life is difficult. In that research, people with dementia and their carers used the phrase “**knowledge is power**” They explained that learning more about dementia helped them feel more confident and better able to deal with challenges.

You can read this research in an academic paper by [Windle et al., \(2023\)](#).

Because of this, the same group helped write the questions used in this evaluation. These questions link directly to what the research said resilience is about. This helps us check whether Knowledge is Power is doing what it was designed to do: help people feel more resilient after a diagnosis of dementia.

What we found out from people with dementia and carers

Hearing directly from people with dementia and their carers helps us know if **Knowledge is Power** is doing what it was created to do. The answers we received were very consistent. Most people said the booklet is **helpful, easy to understand, and gives emotional support**. Almost everyone agreed with the positive statements about it. This shows that the booklet is making a strong and positive difference in people’s lives, especially in helping them feel more confident and more able to cope.



The booklet also seems to make it easier for people to find the help they need. **84%** of people said it helped them **find support**, and **100%** said it helped them **understand what services are available**.

This shows the booklet is filling an important gap. It gives people clear, practical information about what help exists and where they can go next.

The booklet doesn't just help in practical ways — it also seems to help people emotionally. Between **58% and 63%** of people said it helped them see dementia, or themselves, in a new way. These results are positive, but they also show that emotional change is more personal and can take time. Some people may need space to think about the information, or may want to talk it through with someone afterwards. Around a third of people chose “not sure,” which reminds us that the booklet works best when it is offered alongside real support from professionals, carers' services, and peer groups.

Feelings of **hope** and **reassurance** were also very strong themes. Nearly **80%** of people said the booklet “gave me hope,” with only a few people disagreeing. Another **68% to 74%** agreed that **Knowledge is Power** helps them adapt and supports them to keep doing the things they want to do.

These results show that the booklet is not just informative — it also motivates people. It helps them feel more confident and more in control at a time when life can feel confusing or overwhelming.

The one area where people were less sure—but still positive—was about meeting others. **63%** said the booklet helped them learn how to meet other people, while **37%** were unsure.

This is understandable. Meeting new people often depends on things like confidence, what groups exist nearby, and whether someone feels ready. The booklet seems to **open the door**, but some people may still need encouragement or support to take the next step.

This fits with other feedback showing that people benefit from local signposting, in-person help, and community groups alongside the booklet.

Overall, the chart shows a very clear pattern: most people agree with every positive statement about the booklet. People with dementia and their carers see **Knowledge is Power** as helpful and empowering. They say it improves their understanding of services, helps them adapt, and gives them reassurance and hope.

In the few areas where people were unsure, this seems to show a need for extra support, not a problem with the booklet itself.

Most importantly, the responses show that **Knowledge is Power** isn't just being read — it's being **used, felt, and truly valued** by the people who receive it.

We had many open text responses to questions, which provides more detail from people with dementia and carers

People said the booklet was genuinely helpful in their everyday lives. Many explained that it gave them new ideas and helped them understand dementia more clearly. For some, it helped them think in new ways and offered simple, practical tips on how to support others. One person put it really simply: **“It helped me understand the way to help others.”**

A lot of people talked about how easy the booklet is to read. They liked that it's simple, clear, and “not overwhelming”. Many said they appreciated being able to take it home and go through it slowly, at their own speed. This ease of use made people feel relieved—like they finally had information that felt manageable and human, instead of confusing or stressful.

People also valued having “everything in one place.” The booklet acts as a single, trustworthy guide in a world where information is often scattered and hard to find. Some said it helped them learn about services they “didn't realise existed” or “weren't told about anywhere else.” This shows how the booklet helps people find support they may otherwise have missed.

Carers often said they felt more confident after reading it. They liked the practical advice and felt better prepared to deal with daily challenges. Several people even shared the booklet with family members or professionals because they thought it was such a useful guide.

The design of the booklet mattered too. People liked that it was clear, easy to read, and something they could quickly look at again whenever they had questions. One person described it as their “first port of call” when they needed quick help or reassurance.

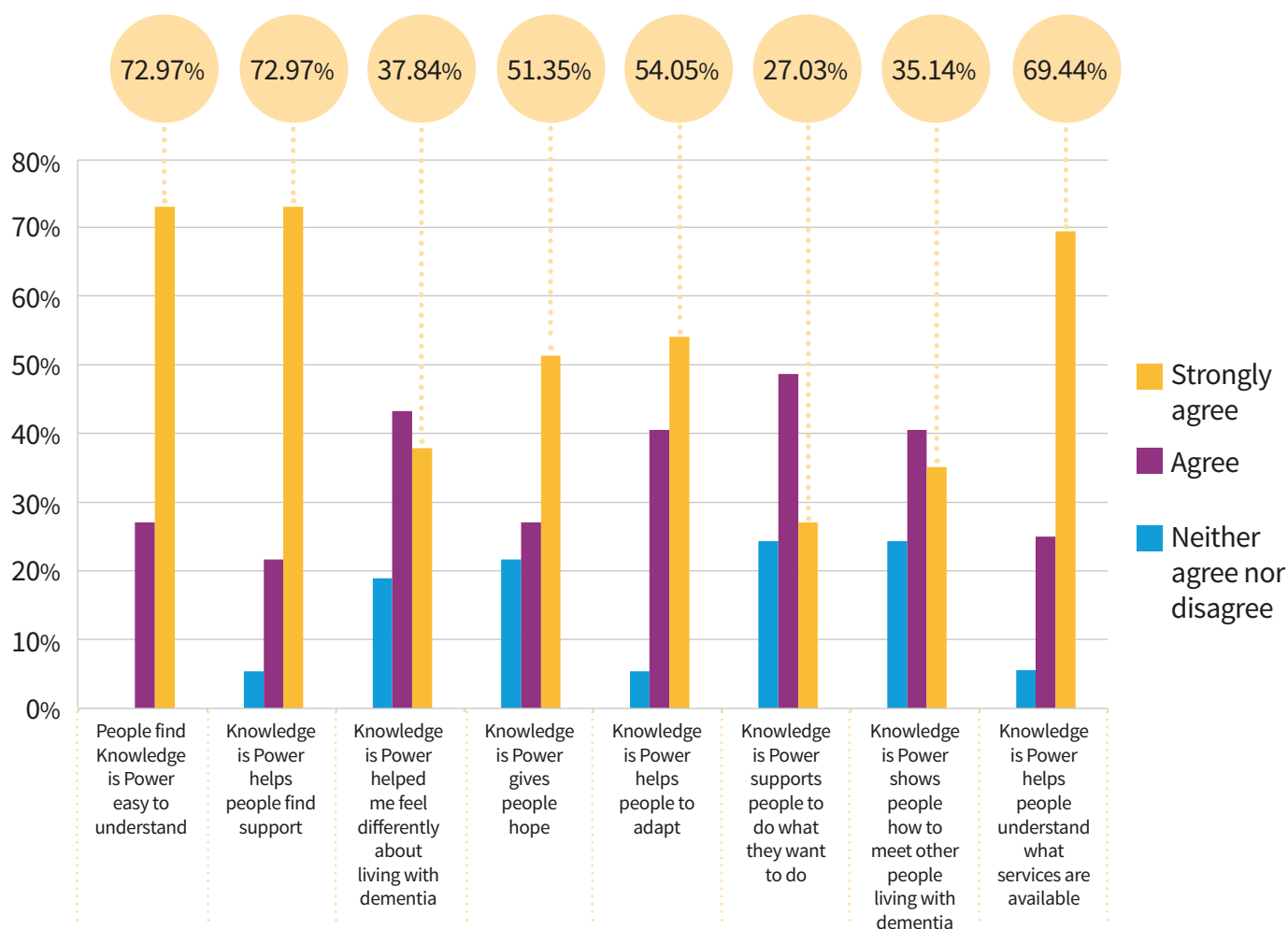
The booklet didn't just help with practical problems—it also offered emotional comfort. Readers said it made them feel calmer and reminded them that they were not alone. For some, it helped them find out where else to go for support. Others said it made them feel more confident, because having good information gave them a sense of control. One person said that giving the booklet to people who “just didn't get dementia” made them feel stronger and more in charge

Lots of people talked about sharing the booklet. They passed it on to friends, family, and even professionals to help them understand dementia better. People strongly valued the fact that the booklet was written by others who actually live with dementia. This made it feel real, practical, and trustworthy.

Not everyone felt it met their needs—one person said it didn't cover their particular situation—but most people said it was a trusted guide, something that boosted their confidence, and a tool they could use to help explain dementia to others. A few mentioned practical issues, like not having enough printed copies or finding it hard when local services differed from the advice. But overall, the message was clear: people with dementia and their carers really value the booklet for being clear, well-organised, warm, and—for many—the thing that helps them feel supported and less alone.

What we found from professionals and volunteers

Responses showed very strong agreement with all statements about the booklet. Most people agreed or strongly agreed that it helps people find support (95%). There was also agreement about Knowledge is Power giving hope (78%) and helping people adapt (95%). Even more complex outcomes—like supporting people to do what they want or helping them meet others—received positive agreement.



Open text responses from professionals gave us more detail.

Professionals said that the people they support react very positively to **Knowledge is Power**. They used strong words like “excellent,” “invaluable,” “very good,” “brilliant,” and even “life changing.” They said the booklet helps people feel less alone, more informed, and more aware of where they can find help. Professionals also said it feels reassuring and practical, and that people appreciated being able to look at it again whenever they need to. One professional called it their “go-to” resource—something people trust when they need clarity or direction.

Several professionals said the booklet helps people realise how much support is actually available. Some readers said things like they “didn’t realise how much support is available” or that the booklet “opened their eyes.” This suggests the booklet doesn’t just give information—it can genuinely change how people understand dementia and what comes next. It helps both people who are newly diagnosed, and the professionals who support them, feel more ready for challenges they didn’t anticipate.



Recommendations for Practice

The following recommendations are grounded in the evaluation of **Knowledge is Power**. While many relate directly to its future development, dissemination, and use, the findings also highlight broader implications for the design and delivery of information more widely. Together, they offer a framework for improving how information supports people living with dementia and those who support them.

1 Embed coproduction as a core principle

Coproduction should remain central to the ongoing development of **Knowledge is Power** and to information provision more broadly. This includes involving people with dementia and carers from the earliest design conversations through to review and dissemination. Lived experience should be recognised as a form of expertise in its own right, ensuring that resources remain authentic, relevant, and grounded in real life.

2 Provide information early—and revisit it over time

Resources such as **Knowledge is Power** should be routinely offered at key points in the dementia journey, particularly at or around the time of diagnosis. They should also be re-offered at later stages, recognising that people's readiness and needs change over time. Information should be understood as an ongoing process rather than a oneoff intervention

3 Prioritise clarity, simplicity, and emotional tone

Clear, accessible language and a straightforward layout are essential to the ongoing success of **Knowledge is Power** and to dementia information more widely. Resources should be designed to reduce overwhelm and enable flexible use, allowing people to engage at their own pace. Maintaining a balance between practical information and emotional reassurance is crucial, ensuring that materials offer both guidance and a sense of hope.

4 Focus on enabling action

Information is most valuable when it helps people take meaningful steps. **Knowledge is Power** should continue to prioritise clear guidance on accessing services, financial support, and future planning, alongside practical suggestions for day-to-day living. Supporting people to move from understanding to action should remain a central aim of all information resources.

5 **Integrate Knowledge is Power into care pathways**

Knowledge is Power should be embedded within routine practice across health, social care, and community services. This includes use during appointments, inclusion in welcome packs, and integration into ongoing support pathways. More broadly, information resources are most effective when used as part of conversations and relationships, rather than as standalone materials.

6 **Maintain accessible formats, including printed copies**

Printed copies of **Knowledge is Power** remain essential for accessibility, usability, and sharing. While digital formats are valuable, they should complement, not replace, physical materials. Ensuring reliable access to both formats will support a wider range of needs and preferences across dementia care.

7 **Strengthen relationship-based distribution**

Effective dissemination of **Knowledge is Power** relies on strong networks and trusted relationships. Continued partnership with professionals, community groups, academic networks, and peer organisations will help ensure the resource reaches people at the right time. Informal sharing and word-of-mouth should also be recognised and supported as important routes of access in wider information provision.

8 **Increase inclusivity and diversity**

Future development and dissemination of **Knowledge is Power**, and dementia information more widely, should actively address gaps in representation. This includes engaging with underrepresented communities, including minority ethnic groups and younger carers, and ensuring that resources reflect a wider range of cultural and social experiences.

9 **Maintain breadth while developing targeted content**

The wide range of topics covered within **Knowledge is Power** is a key strength and should be maintained. At the same time, there are opportunities to deepen targeted content, particularly in relation to carers' experiences, early-stage and pre-diagnosis support, and local signposting. This balance between breadth and specificity is equally important across dementia information resources.

10 Strengthen links between information and ongoing support

Knowledge is Power is most effective when offered alongside relational support. Opportunities should continue to be developed to link the booklet with conversations, peer support, and community connections. More broadly, written information works best when embedded within ongoing human support that helps people reflect, adapt, and act.

11 Ensure information remains current and locally relevant

Regular review and updating of **Knowledge is Power**—particularly around services, benefits, and contact details—is essential. Strengthening local signposting and ensuring information remains accurate will increase trust and usability across all information provision.

12 Promote sharing and wider awareness

Knowledge is Power is frequently shared by readers and acts as a tool for communication and advocacy. Supporting and encouraging this sharing—across families, communities, and professional settings—will help extend its reach and impact. More widely, promoting accessible, coproduced resources can contribute to greater public understanding of dementia.



Final thoughts

A few messages shine through very clearly.

People want and value information that is easy to understand. They want words that feel calm, clear and human, especially at times when life can feel overwhelming.

They also want printed copies they can hold, return to, share with others and keep nearby for when they need reassurance.

People told us they want hope too. Not false reassurance, but a sense that life can still have shape, meaning and possibility after a diagnosis.

.....and perhaps most importantly, they want information created by people who truly understand dementia because they live with it. Readers can feel when something has been shaped by real experience.

This matters because dementia often brings deep uncertainty. A diagnosis can turn life upside down. People may feel frightened, unsure where to turn, or overwhelmed by decisions they did not expect to face.

The responses to our survey make it clear that Knowledge is Power helps in that moment, and long after. It helps people feel understood rather than judged, supported rather than alone, and informed rather than confused. It provides something steady to hold onto at a time when the familiar moorings might seem to be slipping.

For services and policymakers, the message is equally strong.

Co-produced information is not simply a “nice extra.” It has real impact. It helps people act earlier, understand more, and make decisions with greater confidence. It supports professionals by giving them something they trust and can use in their work. And it helps families navigate situations that might otherwise feel impossible.

At its heart, this survey shows that Knowledge is Power works.

People value it, trust it, and use it.

As we look ahead, the task is to keep sharing it widely, keep refining it, and keep placing people with lived experience at the center of every decision.

.....and share the message that dementia might be life-changing.

But it need not be life-ending.

Knowledge is Power

