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Care

Ask the Expert

Seeing the Pattern: How Behavioural Science and AI Can Help Prevent Distress in Dementia Care

Expert: **Dr Emma Williams, Emwillcare Founder**

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When a person living with dementia becomes distressed, the immediate incident is usually managed and recorded. But when observations are scattered across carers, shifts and records, it can be difficult to understand why the same distress keeps happening.

Dr Emma Williams, founder of emwillcare, has worked in care for almost 30 years and is one of around 80 behaviour analysts worldwide specialising in dementia. She created **Less Distress,** her flagship product, to combine behavioural science with AI, helping care teams connect their observations, **recognise individual patterns and respond earlier.**

Q. After almost 30 years working in care, what do you think people most commonly misunderstand about distress in dementia?

People living with dementia are often labelled as aggressive, challenging or difficult. But those **labels do not tell us anything useful about what is actually happening**. They create negative associations with the person rather than helping us understand what they may be experiencing or communicating.

Behaviour happens for a reason. The person might be in pain, frightened, overwhelmed, bored, trying to avoid something distressing or looking for connection. Dementia can affect their ability to explain that in a way we immediately understand, so their behaviour becomes part of their communication.

If somebody becomes distressed during personal care, for example, the answer is not simply to manage or stop the behaviour. We need to understand what it is about that situation that feels frightening, uncomfortable or confusing to them. Once we understand that, we can make changes that protect the person's dignity and often make care easier for everyone.

Q. What did you see happening in care that made you realise a different solution was needed?

I kept seeing the same cycle. A person became distressed; the carers dealt with the immediate situation and the incident was recorded. But it was usually treated as a single event, so the **underlying pattern was not identified and the distress happened again.** One carer might notice that it usually happened in the afternoon. Another might suspect pain. Somebody on a different shift might discover that changing the routine helped. The information was there, but it was spread across different people, shifts and records, so nobody could see the complete picture.

A behaviour analyst would bring those observations together and look for patterns, but there are only around 80 of us worldwide specialising in dementia and access to that expertise is scarce. Less Distress came from asking how we could **make that way of thinking available to far more care teams,** at the point when it could make a difference.

Q. What would using Less Distress actually look like during an ordinary day in a care setting?

A carer records a short, factual observation about what happened before, during and after a person became distressed. **They are not expected to diagnose the cause** or complete a lengthy behavioural assessment.

Less Distress brings that observation together with information recorded by other carers and on other shifts. Over time, **it can identify possible patterns** involving routines, activities, interactions, the environment and the time of day.

For example, it might show that distress is more likely during personal care when the person has just woken up, or that repeated questioning tends to follow long periods without meaningful interaction.

It then helps the team consider what the person might be communicating and what they could try differently. Instead of simply recording yesterday's incident, the information becomes something the team can use to reduce the likelihood of it happening again.

Q. Care providers already record incidents and train their staff. What gap is Less Distress filling?

Incident records are necessary, but they generally document individual events. Training gives carers important knowledge, but it cannot automatically apply that knowledge to one person's changing circumstances across every shift.

The gap is between collecting information and knowing what to do with it.
Less Distress connects observations recorded at different times and by different people, then helps the team apply behavioural thinking to that individual. This is particularly important when staff are busy, teams change and important details can be lost between shifts.

It is not intended to replace existing records or staff training. It makes the information providers already collect more useful and helps staff apply what they have learned more consistently.

Q. How do you make sure the guidance remains individual and grounded in behavioural science?

We start with the person, not with the diagnosis or a label attached to their behaviour.

Two people may both shout, resist personal care or repeatedly ask to go home, but they may be doing those things for completely different reasons. A standard response based solely on the behaviour is unlikely to help both people.

Less Distress considers what happened before the distress, what the person actually did, what happened afterwards and whether factors such as pain, illness, communication or the environment could be involved.

It uses those observations to help the team develop possible explanations and personalised approaches to try. These are informed hypotheses, not definitive judgements. The team can then observe what happens, learn from the person's response and adapt the support accordingly.

Q. What remains uniquely human when AI is involved in this kind of care?

The relationship between the carer and the person remains at the centre of everything.

Technology may notice a pattern across weeks of observations, but it does not know the person in the way their carers and family do. **It cannot replace their knowledge** of the person's history, preferences, expressions, relationships and subtle changes.

Less Distress can bring information together, highlight possibilities and help carers ask better questions. The human being decides whether a suggestion is appropriate, how it should be applied and whether something else, such as pain or illness, needs investigating.

The purpose is not to hand decisions to AI. It is to give carers clearer information so they can use their own judgement with greater confidence and consistency.

Q. What evidence have you seen so far?

The evidence sits at two levels. First, Less Distress is built on established behavioural approaches. We already know the value of looking beyond the behaviour itself, understanding what happens around it and using that information to develop personalised, non-pharmacological support. Less Distress takes that specialist approach and **makes it more accessible,** timely and consistent for everyday care teams.

Second, we have taken the technology from an expert-led idea to a working platform and tested it with carers across real sites. Every carer involved said it could help them **recognise distress earlier** and benefit the person they support. The testing also showed that carers understood the approach and could see how connecting observations across different people and shifts would change the way they responded.

We are now building on that foundation in wider care settings and measuring the effect on repeated incidents, staff confidence, consistency between shifts and the person's experience of care.

Q. What difference could earlier understanding make to the person, their family, the care team and the provider?

For the person living with dementia, it could mean **less fear, greater dignity and more good moments in their day.** Instead of repeatedly experiencing something distressing, the support around them can begin to change.

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Families gain reassurance that their relative is being understood as an individual. Carers gain confidence because they have a clearer idea of what the person may be communicating and how best to respond. It also gives the team greater consistency, particularly across different shifts.

For the provider, that creates the potential for fewer repeated incidents, less staff time spent firefighting, reduced pressure on the workforce and more stable placements. One person's distress affects everyone around them, so understanding it earlier can have a much wider impact.

Q. How do you build trust around privacy, safeguarding and the responsible use of AI?

Trust has to be built into the product and the way it is introduced. Providers should **understand what information is being collected,** why it is needed, who can access it and how it is protected.

Only the information genuinely needed to support the person should be collected. Staff should also understand what **the technology can and cannot do, and who remains accountable for decisions.**

Less Distress is not designed to make clinical decisions or act without human involvement. It helps staff identify patterns and consider possible approaches, but the care team remains responsible for deciding what is appropriate and safe. Responsible AI in care should support professional judgement, not hide or remove it.

Q. What would a sensible first step look like for a provider interested in Less Distress?

I would begin with a focused implementation involving a small number of people and a care team who understand what we are trying to achieve.

We would identify the situations currently causing concern, agree what we want to measure and involve staff from the beginning. They would receive support in using the platform, and we would review their feedback alongside changes in incidents, confidence and consistency.

The provider can then make an informed decision about expanding it to other people, teams or sites. **Being an early adopter should not mean taking a leap of faith.** It should mean testing something carefully, learning from it and only expanding when it is providing genuine value.

Q. Where would you like AI-supported dementia care to be in five years?

I would like us to move away from repeatedly documenting distress after it has happened and towards recognising the circumstances that make it more likely.

That does not mean claiming that every incident can be predicted or prevented. Dementia and human behaviour are far too complex for that. It means using the information care teams already gather more intelligently, so that **warning signs and recurring patterns are less likely to be missed.**

I would also like personalised behavioural support to be available to far more people. At present, access to specialist behavioural expertise is extremely limited.

If we use AI responsibly, it can help extend that expertise, improve continuity between shifts and give carers practical support while keeping human relationships and judgement at the centre of care. That is the future Less Distress is being built for.

See the pattern. Understand the person. Change the outcome.

Distress in dementia care doesn't happen without reason. The challenge is recognising the patterns behind it and turning everyday observations into meaningful insight.

Technology can help care teams bring those observations together, identify what may be driving distress and respond with greater understanding, consistency and confidence.

Access brings care planning, rostering, eLearning and Technology Enabled Care together, helping teams spend less time on administration and more time delivering person-centred care.

Because when we understand the pattern, we can better understand the person.

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