The Culture and Practice Model

of the Young Onset Dementia Service

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol Caerdydd a'r Fro
Cardiff and Vale University Health Board

Relationship-centred • continuity-based • psychologically informed



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Continuity of care is a clinical intervention

The pathway combines planned review with responsive access when circumstances change.



Diagnosis	Ongoing review	Emerging need	More intensive support
Engage early	Six-monthly outpatient review + open door	Proactive response and assessment	Wider YOD Therapies MDT + named Care Coordinator when required

The practical effect: opportunities to identify evolving needs before they escalate into crisis.

A model shaped by long-term relationships

Established in 2011 and designed to remain alongside people as needs evolve.

The service extends beyond traditional post-diagnostic support. Its defining proposition is that culture is not incidental to clinical practice: it is part of how effective care is delivered.

Relationships

Sustained engagement and trust

Continuity

Support across the illness trajectory

Community

Belonging beyond professional services

Relationship-centred, not task-centred

Care is more than information, medication review and practical planning.

What the model adds

1. **Engagement with lived experience**
2. **Trust built over time**
3. **Space for the existential impact of diagnosis**
4. **Relational capital for difficult future decisions**

Understanding is much deeper than knowledge. There are many who know you, but very few who understand you.



Community, belonging and peer support

Professional services cannot meet every need associated with young onset dementia.

Community activity as an intervention

Cognitive Stimulation Therapy

Walking groups and craft activities

Dementia Café / Attached Carers Support Group / third-sector links

Peer relationships that can emerge organically

The purpose extends beyond recreation: social engagement can support belonging, shared understanding and psychosocial adjustment.

A practical illustration: the annual Clients and Carers Day Out

A community setting used for CST, connection and mutual support.

26

clients and carers attended

2 September
St Fagans National Museum of History

The day was structured around CST activities and opportunities for people to meet others facing similar circumstances.

Connect

Mutual support and new relationships

Engage

Reminiscence, museum exhibits and CST

Grow

A wider service-user led network

Complexity needs reflective multidisciplinary practice

“Inquisitorial, not adversarial”

Good MDT reasoning tests assumptions rather than seeking superficial agreement.

Capacity & autonomy

Risk & safeguarding

Family dynamics

Progressive cognitive decline

Proportionality & least restriction

Aim: evidenced conclusions that can hold uncertainty and competing principles.

Culture is a clinical asset

The YOD model brings together four mutually reinforcing elements.

RELATIONSHIPS
Human connection and empathic engagement

CONTINUITY
Staying alongside people as needs evolve

COMMUNITY
Belonging, activity and peer support

REFLECTION
MDT challenge and support for staff

Clinical effectiveness can only really be achieved if it sits inside a “culture of care”.

Caring for the staff who deliver the care

Relational work is emotionally demanding, so support for staff is part of safe practice.

“You cannot pour into others if your own cup is empty.”



Informal peer support

MDT reflection

Supervision

Dedicated whole-team psychology sessions

Co-location that enables day-to-day mutual support

The trauma of hospital admission

Admission is not simply a change of care setting, but a profound emotional transition for carers and families.

STIGMA & FEAR

Being “sectioned” can carry powerful meanings: stigma, fear, a sense of failure and uncertainty about what the future now holds. To be ‘sectioned’ the law as a verb laden with stigma.

GUILT & LOSS

Carers may question whether they have let the person down or worry that others will think they no longer care.

COMPLICATED RELIEF

Being told to feel relieved because there is now a “break” does not remove distress. For some carers, admission can make feelings worse.

CARING DIFFERENTLY

Caring does not stop at the hospital door. The relationship continues, but the way care is expressed may need to change.

“Caring doesn’t stop, it never will. It is right now to care differently.”

‘You have all been an invaluable help to our family during this very difficult journey with mum.

We truly appreciate you all and the amazing work that you all do.

We just wanted to say a huge thank you for supporting mum with kindness, care, and understanding.

Thank you for always embracing her for who she was, even as dementia changed things.

“The Young Onset Dementia Service has been life changing for us during the last few years. When my husband was first referred we only expected regular outpatient appointments. How wrong we were. The level of engagement across the various parts of the service has been outstanding. We are so grateful for the continuity of support, which works very effectively.

Staff have been friendly, informative and helpful. What I value most is the transparency with which things are done and the unique way in which staff treat both patient and carer. There is a true feeling of togetherness, rather than us and them. Everyone has gone the extra mile to enable us to cope with the challenges we have been faced with.”