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Improving care co-ordination for people with dementia in Inverclyde

Care Co-ordination in the Community Improvement Programme overview 2019-2022

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Introduction

Context

While effective care co-ordination for people living with dementia and their carers exists in Scotland, there remains inconsistency and variation in both practice and service provision.

> Care co-ordination' refers to:
>
> *"a proactive approach to bringing together care professionals and providers to meet the needs of service users to ensure that they receive integrated, person-focused care across various settings.[1]"*
>
> World Health Organisation

Without continuity and co-ordination of care and support, people with dementia, carers and families can experience fragmented and poorly integrated care from multiple providers. Duplication of effort and avoidable hospital admission are often the result.

Scotland's third national dementia strategy highlights the importance of co-ordinated care for people with dementia[2]. The Care Co-ordination in the Community Improvement Programme was commissioned by the Scottish Government to improve access to high quality care co-ordination for people with dementia and carers in the community. Focus on Dementia, part of the Improvement Hub (ihub) at Healthcare Improvement Scotland, were the national lead for the programme on behalf of the Scottish Government. We worked in partnership with Alzheimer Scotland and collaborated with a number of local and national health and social organisations and practitioners including NHS Education for Scotland and Public Health Scotland. We also engaged with people with dementia and their carers throughout both programmes.

Overview

Inverclyde Health and Social Care Partnership (HSCP) was selected as the dementia care co-ordination programme implementation site after an application and selection process. The two year programme of work supported improvements and redesign of community-based services to improve the experience, safety and co-ordination of care, services and support for people living with dementia from diagnosis to end of life. The emphasis was to support people to stay well at home or in a homely setting for as long as possible.

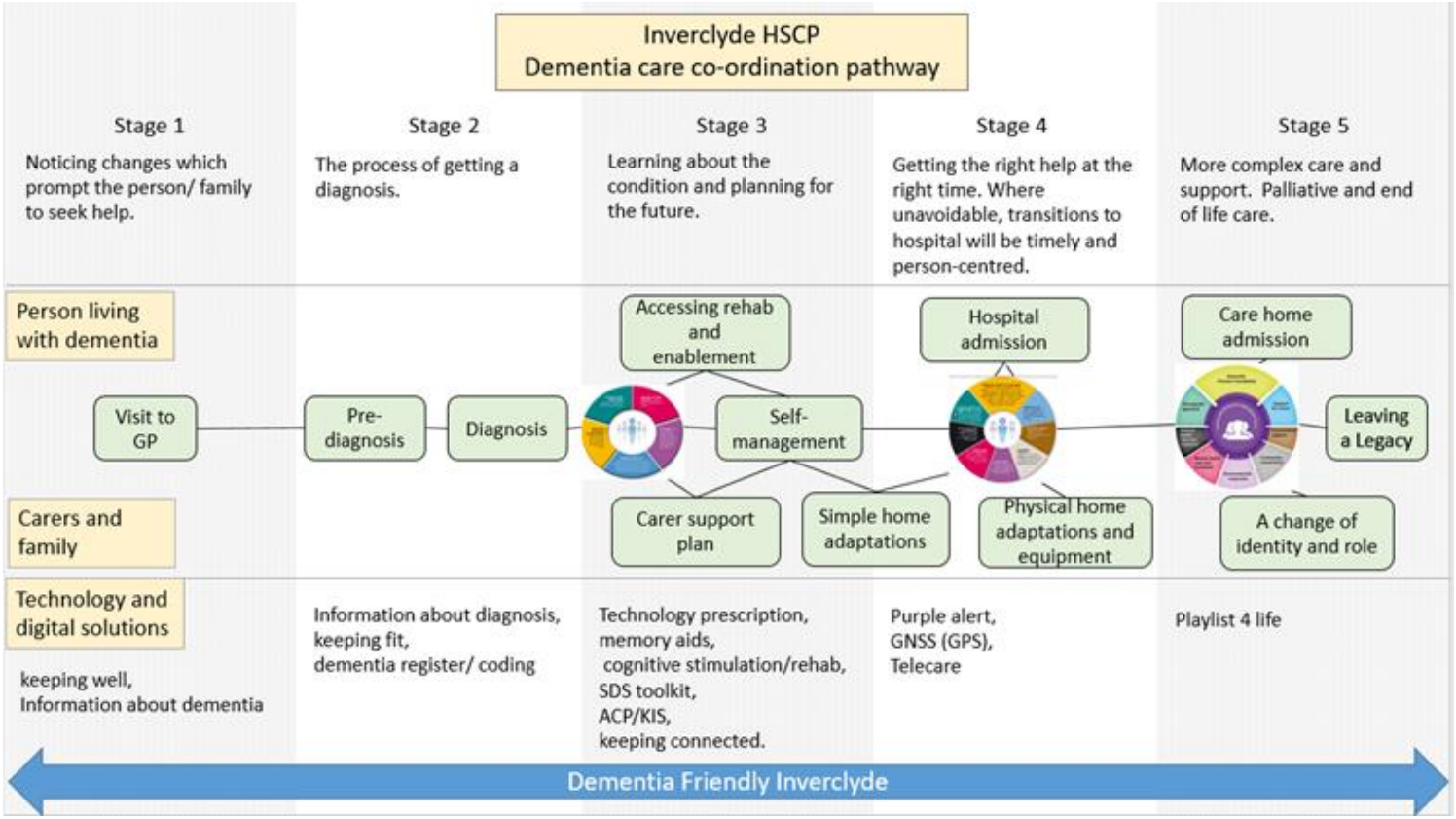
Taking a whole systems and pathway approach from diagnosis to end of life, the programme aimed to:

- improve care co-ordination for people with dementia and their carers
- develop and evaluate a model of effective care co-ordination for people with dementia and their carers, and
- share learning across NHS Greater Glasgow and Clyde, Scotland and further afield.

Method

Scope

The programme focused on the full dementia care co-ordination pathway, shown in the diagram below.



Quality improvement methods

Our role is to support those delivering health and social care across Scotland to redesign and continuously improve services to ensure they meet the changing needs of people in Scotland. We do this by using different quality improvement methods and approaches. This programme involved the implementation of previous learning into Inverclyde's particular context (for example the previous testing of the 8 Pillar model of care co-ordination) and the testing of new approaches (for example, the Advanced Dementia Practice Specialist team approach) in order to inform future practice and wider sharing of learning across Scotland. Before delivering a programme of work it is crucial to agree what the aim of the programme is, what "drivers" might influence you achieving your aim and what changes are likely to lead to your desired aim. Creating a driver diagram identifies steps required to achieve your aim.

The design of this programme was informed by:

- models of support including:
    - 5 Pillars Model of post-diagnostic support (PDS)
    - 8 Pillars Model of Community Support
    - Advanced Dementia Practice Model
- Care Co-ordination in the community for people with dementia in Midlothian appreciative inquiry and data analysis, and
- the extrapolation of the twelve Dementia Care Co-ordination Critical Success Factors.

Our theory of change is set out in our driver diagram below.

Aim

To improve care co-ordination for people with dementia and their carers in Inverclyde from diagnosis to end of life by March 2021

Primary drivers

Care co-coordination of pre-diagnosis/diagnosis support (stage 1 and 2)

Care co-ordination of PDS (stage 3)

Care co-ordination of increasing support needs (stage 4)

Care co-ordination of palliative and end of life care (stage 5)

Secondary drivers

Dementia friendly GP practices

Accessible information on dementia

Timely diagnosis

Timely person-centred access to PDS

Single point contact

Identify, understand needs of and monitor all individual's with dementia

Robust communication between stakeholders

Proactive assessment of house and home

Proactive monitoring and interventions for changing needs

Support for carers

Care management for complex needs

Proactive identification of PEOLC needs

Access to appropriate care home places

Change ideas

- Dementia register
- Implementation of dementia friendly toolkit
- eFraility work to identify individuals
- Primary care diagnosis for non-complex cases
- Self/supported referral to AHPs at all stages
- PDS waiting list/referral triage – 8 pillars to wider team
- Group/peer support
- Online information resource
- Hub for information and support
- Personalised technology prescription
- ISD identification of people living with dementia
- Support local implementation of Connecting People, Connecting Support
- Co-ordinated approach to the delivery of PE Framwork across system
- Weekly team meeting
- Self referral when things changed
- Fraility at the Front Door and acute care identification
- Mechanism/process to share information with stakeholders
- Technology to keep people living with dementia and carers connected
- Use of Rockwood frailty monitoring by community teams
- Support group for carers of people with advanced dementia
- Home care in sheltered housing
- Implementation of Dementia and Housing Framework
- Liaison with palliative care specialists
- Testing of ADPM
- Stress and distress/dementia/ PEOLC training

Our full change package from our post-diagnostic support and care co-ordination work containing a driver diagram and measurement plan can be found on the ihub website.

Project team

Funding associated with the programme allowed Inverclyde HSCP to recruit an improvement advisor to lead and co-ordinate the programme and work with national and local stakeholders.

The work was supported through a local steering group, operational group, and a range of work stream subgroups including:

- Advanced Dementia Practice Model
- Learning Disabilities and Advanced Dementia
- Data and Evaluation, and
- Identification tools for Palliative and End of Life care (PEOLC) group.

Arrangements were agreed to involve the Inverclyde Dementia Reference Group, which is a local group for people living with dementia and their carers. The group have been instrumental in informing and supporting key areas of work.

Stakeholders

The programme has actively involved a range of stakeholders throughout.

Ninety-two stakeholders attended the launch event in September 2019, including people living with dementia, carers and representatives from local and national organisations. Priority areas were identified at the event and informed the overall programme action plan.

Shared learning, progress updates, improvement ideas and action planning have been generated through five learning sessions.

Our stakeholder engagement

Date	Type of event	Attendees	Summary
27 September 2019	Stakeholder event	92 attendees including people living with dementia, carers and representatives from local and national organisations	Our attendees had the opportunity to learn more about this work, and joined us in mapping the different stages of the dementia pathway and to begin to identify improvement themes to inform this work.
5 December 2019	Learning session	39 staff	Our session focused on quality improvement methods including plan, do, study, act cycles.
6 March 2020	Learning session	64 staff	64 staff attended the sessions where there was a focus on data for improvement.
16 December 2020	Learning session	25 staff	This session focused on agreeing improvement ideas for effective care co-ordination for people living with dementia and their carers in Inverclyde. The session included a presentation on a case study on the experience of a person living with dementia.
27 April 2021	Learning session	51 staff	This session focused was on exploring the role of care co-ordination, the different levels of care co-ordination, examples in practice and identify and discuss ideas to improve care co-ordination in Inverclyde to inform programme action planning.
22 October 2021	Learning session	49 staff	This session focused was on assisting local service providers to meet the needs of people with dementia and their carers by enhancing knowledge about what supports are available and how they can be accessed. Attendees also had the chance to hear from representatives from local services.

Timescales

The programme was commissioned in April 2019. During the first wave of the COVID-19 pandemic the programme went into hibernation for six months to ensure no additional pressure on frontline services.

The programme was safely recommenced in September 2020 and, to mitigate impact from the pandemic, the Scottish Government agreed funding for an additional year until March 2022. The programme priorities and action plan were reviewed following recommencement, taking account of what was achievable before March 2022.

Outputs

Throughout the duration of the programme's implementation, a number of outputs and impacts have been generated in relation to both post-diagnostic support and care co-ordination. These are explored in turn below. We have shared links to our key resources where available. If you are interested in finding out more about any outputs not available online, please contact the team at his.focusondementia@nhs.scot for more information.

Output	Summary	Key resources
Post-diagnostic support		
Weekly meetings.	A weekly review of PDS waiting list meeting is valued and is sustained within Inverclyde. An evaluation of the weekly meeting were carried out and found better collaboration between Alzheimer Scotland and Inverclyde HSCP. It facilitated wider discussion around service objectives and alignment to Alzheimer Scotland and Inverclyde HSCP strategies and goals.	Further information available on request.
Single quality question (SQQ).	People living with dementia and their carers were involved in a national initiative to testing a PDS "single quality question" to support the evaluation the PDS service provision. Inverclyde have now incorporated the SQQ as part of Inverclyde's PDS service.	Testing the feasibility and usability of a post-diagnostic support single quality question (ihub).
Quality Improvement Framework (QIF).	The QIF, which sets out criteria for high quality post-diagnostic support for people living with dementia has been completed and an improvement plan implemented.	Quality Improvement Framework (ihub).

Output	Summary	Key resources
PDS Service Standard Operating Procedure – including data requirements.	A PDS standard operating procedure had been developed which includes ensuring local PDS data is captured. All new referrals to PDS who are open other to other HSCP services are identified, an alert is added to EMIS (the local database for the collection and dissemination of patient information) and are informing other services of dementia diagnosis and PDS support.	Further information available on request.
Housing and Anticipatory Care Planning.	After receiving training, the local PDS workers are now having, where appropriate, housing and anticipatory care planning conversations.	Scottish housing and dementia framework (Chartered Institute of Housing).
Care co-ordination		
Mapping care co-ordination in Inverclyde.	This applies to the stage of the dementia journey when people are living at home and are supported to live independently and remain connected to their community, for as long as possible, as dementia progresses. This is aligned to the Alzheimer Scotland 8 Pillars Model of Community Support. In October 2021 we hosted our fifth programme learning session. The purpose of this was to increase awareness of services and supports for people living with dementia and carers. This was requested following feedback from participants who attended the fourth learning session.	Further information available on request.

Output	Summary	Key resources
Care co-ordination role Inverclyde.	The programme has drafted a document that describes the delivery of care co-ordination and the care co-ordinator role in Inverclyde. We have mapped existing services in Inverclyde to Alzheimer Scotland 8 Pillars Model of Community Support, (figure 3). The model provides a coordinated and strategic framework for effective and integrated community support for people living with dementia and their carers. It addresses treatment of symptoms and aims to improve the resilience of people with dementia and their carers supporting them to live well and independently for as long as possible. It recognises that for people living with dementia to have optimal wellbeing both health and social needs required to be met.	Further information available on request.
Collating services document.	Following feedback from Inverclyde services during learning session four better understanding of roles and responsibilities and services and support was required to improve care co-ordination. A service specification resource was developed as a result.	Further information available on request.
Reviewing Inverclyde against twelve critical success factors for care co-ordination.	In partnership with programme stakeholders, Inverclyde has completed the twelve Critical Success Factors self-assessment with an associated improvement plan. This will be carried over into the future dementia strategy arrangement.	Further information available on request.
Advanced Dementia Practice.	Testing of the Advanced Dementia Practice Model was a requirement of this commission. A working group was established to agree Inverclyde's application.	Advanced Dementia Practice Model (Alzheimer Scotland).

Output	Summary	Key resources
Identification tools for PEOLC.	A short life working group was established to agree an identification tool or a basket of tools for staff from clinical and non-clinical backgrounds to identify when dementia is advancing and ensure appropriate supports are in place. This work has concluded, it was not possible to agree on one specific PEOLC identification tool, it depends on its purpose and who is using this. Inverclyde will await publication of SIGN guidance. PEOLC knowledge and skills will be incorporated into planned dementia workforce development across Inverclyde.	Further information available on request.
Advanced Dementia Specialist Forum (ADSF).	The Advanced Dementia Specialist Forum has been tested for a period of 6 month and has now been evaluated. The evaluation paper includes a number of recommendation should the ADSF continues. This will be considered for the future dementia strategy arrangement.	Further information available on request.
Learning Disabilities and Advancing Dementia.	A need was identified by Inverclyde Community Learning Disability Team relating to the care home placement of an individual with a learning disability and advancing dementia. A short life working group was established involving local and national partners. The group has agreed to draft a guidance document for staff to support people with a learning disability and advancing dementia moving to move into a care home.	My New Home (ihub)
Whole Pathway Improvements.	A requirement of the programme is to explore the use of digital solutions to transform services. This aims to support people living with dementia to live well and independently for as long as possible. A short life working group was established to develop the app and content. The Dementia Reference Group helped design an app to support people with dementia and their carers live well with dementia. This work is continuing beyond the timescales of the programme.	Further information available on request.

Output	Summary	Key resources
Workforce Development.	The ambition for Inverclyde is to have a sustainable dementia workforce training and development plan in place. The programme aims to ensure the workforce of Inverclyde, who support people living with dementia and their carers, have the appropriate knowledge and skills to support them to live well and live independently for as long as possible within their own community throughout their dementia journey. This plan will include health, social care, third sector, community groups, volunteers, housing and care home staff. A dementia training co-ordinator is now in post, and a training plan is currently being implemented.	Further information available on request.
Housing.	Inverclyde is implementing the Dementia and Housing Framework and will be linking in with local training co-ordinator in relation to housing training plans. A number of activities are planned including questionnaires, identifying current awareness of and use of the Housing and Dementia Framework. A summary report of feedback and implementation plan, including sign up of the Framework Implementation of Dementia awareness and training, Dementia Friends, Informed Level of Promoting Excellence Framework with a focus on housing.	Scottish housing and dementia framework (Chartered Institute of Housing).
Dementia Friendly Communities.	Your Voice has been awarded the contract for the Dementia Friendly and Enabled Inverclyde programme. Over 130 people with dementia and carers have so far been involved in its implementation. Logos and branding have been co-produced and development plan is in place.	Your Voice. Dementia friendly communities (Alzheimer Scotland).

Output	Summary	Key resources
Allied health professional (AHP) contribution.	AHPs have a key role in supporting people living with dementia and their family and or carers. Progress has been made in exploring and enhancing the AHP contribution to an integrated and co-ordinated approach as outlined in the Alzheimer Scotland AHP framework; Connecting People, Connecting Support. Inverclyde occupational therapists have been implementing Journey Through Dementia and Homes Based Memory Rehab.	Connecting People, Connecting Support (Alzheimer Scotland).
Data and Measurement.	Inverclyde have been working with local and Scottish Government analysts to better understand their population of people living with dementia and how they use services. They have developed a measurement framework going forward and are designing a register of people living with dementia.	Further information available on request.

Impact

An external evaluation has been conducted to capture the impact of this work. Our evaluation can be viewed on our webpages[3].

Outcome	Examples of our achievements
A personalised and human rights-based approach to care that empowers individuals to self-manage and live independently for longer.	Early intervention was important to prevent people with dementia going into residential care prematurely. The programme supported initiatives to facilitate people with dementia to continue to live independently. This included: • developing links between HSCP services, and with the third sector, and • supporting development of resources including a leaflet and self management App[3].
A better person experience, improved quality and better outcomes for people in the area living with dementia and their carers.	The evaluation highlighted the importance of joined-up care for service delivery, and the importance of good communication in order to do this. The evaluation also highlighted the importance of linking with both the Dementia Reference Group, and the ADSF for ensuring that the views of people with dementia and their carers, and for providing knowledge on available resources respectively[3].
A more integrated and co-ordinated approach across the whole system which enhances connections and improved collaboration across health and social care.	The evaluation found evidence that services wanted to work together, strong leadership within the programme and Inverclyde, and learning opportunities delivered as part of the programme[3].

Outcome	Examples of our achievements
Effective monitoring and measurement approaches that can adequately assess the effectiveness and quality of the 'whole system' locality approach.	The evaluation found evidence of measurement and monitoring, for example the development of a Dementia Measurement and Performance Framework[3].

Sharing our learning

Learning from the programme has been spread through our learning system activities. We have also shared through a number of events.

Event	Date	Summary
PDS network	On-going	This network of PDS Leads from across Scotland meets every 3 months to share good practice in supporting people living with dementia. They provide an opportunity for leads to engage with national partners including Focus on Dementia, Public Health Scotland, Dementia Policy Team, Alzheimer Scotland and NHS Education for Scotland.
IHI National Forum	10-11 December 2019	An oral presentation was given at the event in Orlando in December 2019. This event hosts over a 5,000 international delegates.
Alzheimer Scotland Conference	21 September 2021	An oral presentation was given at the online event.

Event	Date	Summary
Participation Research Network Webinar: Involving people with Dementia	18 November 2021	The Participation Research Network is an opportunity to share learning, best practice and exciting news about public engagement research and public participation projects with a health or care focus. It is open to practitioners, policy makers, researchers and everyone with an interest in sharing evidence on participation (public involvement, engagement, co-production) in health and social care. 71 attendees joined via MS Teams to hear members of the project team present on the programme in Inverclyde and how it included people living with dementia and carers.
Alzheimer Europe Virtual Conference	30 November 2021	We showcased the care co-ordination twelve Critical Success Factors work via a pre-recorded presentation at the 31st Alzheimer Europe Virtual Conference "Resilience in dementia: Moving beyond the COVID-19 pandemic" brings together over 600 participants from 38 countries.
Alzheimer Disease International (ADI)	9-11 June 2022	An oral presentation was given at the event in London in June 2022. This event hosts over a 1,000 delegates from over 100 countries.
Alzheimer Scotland Conference	5 September 2022	An oral presentation was given at the event in Edinburgh in September 2022.
Alzheimer Europe Conference	17-19 October 2022	An oral presentation was given at the event in Bucharest in October 2022 to share the publication of My New Home (ihub)

Conclusions

Despite being impacted by the COVID-19 pandemic, the Care Co-ordination in the Community Improvement Programme has made significant progress to improve the care and support of people living with dementia and their carers. It has also lead to new learning and produced new resources that would be beneficial to other areas in Scotland. Some lesson principles have been listed below.

- Being clear about project roles and responsibilities.
- Meaningful stakeholder engagement including people with lived experience and stakeholders across all sectors. Examples of stakeholder engagement included the stakeholder event, Dementia Reference Group, commissioned interviews with people with lived experience and staff.
- Project infrastructure including the Operational and Steering Group.
- Quality improvement methodology and project management support.
- Truly integrated approach.
- Having a “Lead” that is able to make strategic decisions.
- Using a whole pathway approach.
- Care co-ordination critical success factors as a framework.

The learning from this work and from our other community work will be packaged into a set of high impact changes and will be shared across Scotland.

Acknowledgements

Thank you to everyone who supported the delivery of this work including people living with dementia and their carers, staff in Inverclyde HSCP, colleagues in Healthcare Improvement Scotland and colleagues in our partner organisations.

References

1. World Health Organisation. Continuity and coordination of care: A practice brief to support implementation of the WHO Framework on integrated people-centred health services. 2018 [cited 12 Aug 22]; Available from http://apps.who.int/iris/bitstream/handle/10665/274628/9789241514033-eng.pdf?ua=1#:~:text=Care%20coordination%3A%20a%20proactive%20approach,focused%20care%20across%20various%20settings.
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