Inverclyde council

AGENDA ITEM NO: 5

Report To:	**Health & Social Care Committee**	**Date:**	**19 August 2021**
Report By:	**Louise Long** **Corporate Director, (Chief Officer)** **Inverclyde HSCP**	**Report No:**	**SW/17/2021/AM**
Contact Officer:	**Anne Malarkey** **Head of Mental Health, ADRS and Homelessness**	**Contact No:**	**715284**
Subject:	**Dementia Care Co-ordination Programme Update**		

1.0 PURPOSE

1.1 The purpose of this paper is to provide the Health and Social Care Committee with a progress report on the Inverclyde Dementia Care Co-ordination Programme.

2.0 SUMMARY

2.1 As part of Scotland's third National Dementia Strategy, Inverclyde HSCP was selected as the Dementia Care Co-ordination Programme implementation site. The Programme is supporting improvements and redesign of community based services to improve care co-ordination for people with living with dementia from diagnosis to end of life.

2.2 The Programme was due to end in March 2021, however during the first wave of the Covid-19 pandemic, the programme went into hibernation for 6 months. It was safely recommenced in September 2020 and, to mitigate impact from the pandemic, the Scottish Government have agreed to fund the Programme for an additional year until March 2022. The Programme priorities and action plan were reviewed following recommencement, taking account of what is achievable between February 2021 and March 2022.

2.3 Priority areas for improvement include care co-ordination for people newly diagnosed with dementia, ensuring a responsive and sustainable Post Diagnostic Support service; care co-ordination for people living with moderate dementia. This will be aligned to the 8 Pillars Model of Community Support and 12 Critical Success Factors for effective care co-ordination; and care co-ordination for people living with advanced dementia at a palliative and/or end of life stage by testing Alzheimer Scotland Advanced Dementia Practice Model.

In addition the following actions will be implemented: Creating a sustainable approach to dementia workforce development; Clarification of roles and responsibilities and service pathways; Development and testing of a self-management leaflet and app; Local implementation of the Dementia and Housing Framework; Enhancement of the Allied Health Professional contribution to an integrated and co-ordinated approach; Improvement in the completion and consistency of Anticipatory Care Planning for individuals with dementia and; re-establishment of Dementia Friendly and Enabled community work.

2.4 A Programme measurement plan is being agreed and the Scottish Government are in the process of commissioning an external evaluation. A requirement of the Programme is to share learning across NHS GGC and Scotland and the steering group are in the early stages of discussions about arranging an end of Programme shared learning session. Discussions are also planned with stakeholders to consider the sustainability of the Programme priorities at the end of the Inverclyde Dementia Care Co-ordination Programme in March 2022.

3.0 RECOMMENDATIONS

3.1 The Health and Social Care Committee are asked to note the contents of this paper, Programme achievements and action planning until its conclusion in March 2022.

Louise Long
Corporate Director (Chief Officer)
Inverclyde HSCP

4.0 BACKGROUND

4.1 As part of Scotland's third National Dementia Strategy, Inverclyde HSCP was selected as the Dementia Care Co-ordination Programme implementation site. The Programme is supporting improvements and redesign of community based services to improve the experience, safety and co-ordination of care, services and support for people with dementia from diagnosis to end of life. The emphasis is on supporting 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, by March 2022, the programme aims to:

- Improve care co-ordination for people with dementia and their carers
- Develop and evaluate a model of effective care coordination for people with dementia and their carers
- Share learning across NHSGGC, Scotland and further afield.

4.2 Healthcare Improvement Scotland (HIS) are the National lead for the Programme on behalf of the Scottish Government. Funding associated with the Programme has allowed Inverclyde HSCP to recruit an Improvement Advisor to lead and co-ordinate the Programme and work with national and local stakeholders.

4.3 The Programme has actively involved stakeholders throughout. 92 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 four Learning Sessions. Arrangements were agreed to involve Inverclyde Dementia Reference Group (DRG). The DRG have been instrumental in informing and supporting areas of work, e.g. participated in local stakeholder engagement work commissioned by HIS; development of a self-management leaflet; a single quality question for the Post Diagnostic Service; shared their experiences during the first wave of the pandemic, which was used to inform national policy.

4.4 The Programme was due to end in March 2021, however during the first wave of the Covid-19 pandemic, the programme went into hibernation for 6 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 have agreed to fund the Programme for an additional year until March 2022. The Programme priorities and action plan were reviewed following recommencement, taking account of what was achievable from February 2021 to March 2022. Agreed priorities are listed in table 1:

Table 1: Dementia Care Co-ordination Programme Priorities February 21 to March 22

Actions: Dementia Pathway	**Actions: Cross Pathway**
Care co-ordination for people newly diagnosed with dementia, ensuring a responsive and sustainable Post Diagnostic Support service.	- Workforce Development - Clearer roles and responsibilities - Clearer service pathways including GP practices - Self-management leaflet and app - Dementia and Housing - Enhance the Allied Health Professional contribution to an integrated and co-ordinated approach - Anticipatory Care Planning and dementia - Dementia Friendly and Enabled community (aligned to Programme) - Measurement plan and evaluation
Care co-ordination for people living with moderate dementia. This will be aligned to the 8 Pillars Model of Community Support and 12 Critical Success Factors for effective care co-ordination.	
Care co-ordination for people living with advanced dementia at a palliative and/or end of life stage by testing Alzheimer Scotland Advanced Dementia Practice Model.	

4.5 **Post diagnostic support (PDS) - a sustainable model**

Everyone newly diagnosed with dementia is entitled to receive a minimum of one year's post-diagnostic support, co-ordinated by a named Link Worker and will have a person-centred support plan in place. This is centred on Alzheimer Scotland 5 Pillars Model of Post Diagnostic Support. There is a PDS Local Delivery Plan (LDP) Standard in place which is reported in two parts:

1. The percentage of people estimated to be newly diagnosed with dementia who were referred for post diagnostic support – this is reported Scotland wide and by Health Board area.
2. The percentage of people referred who received a minimum of one year's support – this is reported Scotland wide, by Health Board and HSCP.

Data is exported to Public Health Scotland (PHS) from GGC collectively. Management Information Reports detailing performance against the Dementia Post-Diagnostic Support LDP Standard are provided by PHS quarterly.

LDP Standard Performance: The percentage of people estimated to be newly diagnosed with dementia who were referred for post diagnostic support.

This part of the LDP standard requires the actual numbers diagnosed and referred for PDS, as a percentage of the estimated incidence. Table 2 presents the proportion of people estimated to be newly diagnosed with dementia who were referred for PDS up to 31st March 2021. At the time of this report, 2016/17 to 2019/20 referral data is complete, 2020/21 is provisional. Less than half of the estimated projected numbers are diagnosed and referred to PDS across Scotland and NHS GGC. Data for 2020/21 has been impacted by the Covid-19 pandemic as there was a significant reduction in numbers diagnosed across Scotland.

Table 2: Proportion of people estimated to be newly diagnosed with dementia who were referred for PDS

Year	Scotland	NHS GGC
2016/17 (complete)	44.6%	42.7%
2017/18 (complete)	42.3%	43.1%
2018/19 (complete)	42.8%	47.4%
2019/20 (complete)	40.7%	42.6%
2020/21 (provisional)	29.6%	31.1%

LDP Standard Performance: The percentage of people referred who received a minimum of one year's PDS.

This element of the Standard is reported Scotland wide, by Health Board and by HSCP. There are two elements that are required to meet the Standard:

- PDS must commence, that is first direct intervention with a PDS Practitioner or team within one year from date of diagnosis and;
- A minimum of one year PDS is recorded from first direct intervention with a PDS Practitioner or team to PDS termination or transition date.

It can take up to two years from date of dementia diagnosis to complete PDS and LDP Standard requirements. Table 3 presents the proportion of people referred who received a minimum of one year's PDS up to 31st March 2021. Data for 2016/17 is now finalised and published, during this time Inverclyde HSCP compliance is 68.5%, which is less than Scotland wide and higher than NHS GGC collectively. Remaining yearly reports are still provisional and plans are in place to improve LDP Standard compliance. Please note 2020/21 data for Inverclyde is based on only 7 referrals where PDS recording is complete at time of the report. Two referrals were recorded as having met the LDP standard and 5 referrals were recorded as not meeting the standard due to PDS being completed early (calculations 2/7X100 = 28.6%). 56 referrals out of 63 received for this reporting period have PDS ongoing at the time of the report.

Table 3: Proportion people referred who received a minimum of one year's PDS			
Year	**Scotland**	**NHS GGC**	**Inverclyde**
2016/17 (complete)	75.5%	66.5%	68.5%
2017/18 (provisional)	73%	62.6%	77.4%
2018/19 (provisional)	76.1%	64%	57.1%
2019/20 (provisional)	78.4%	56.6%	54.9%
2020/21 (provisional)	59.3%	43.1%	28.6%

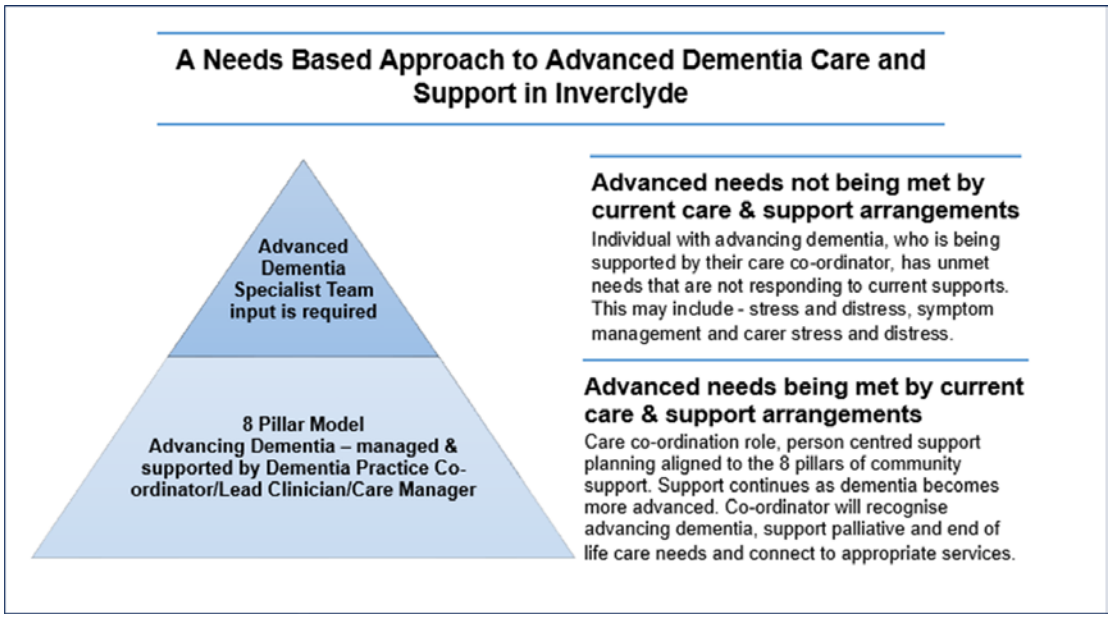
A number of areas for improvement have been identified and agreed that will ensure a responsive and quality PDS service for Inverclyde. There have been a number of service challenges over the last year. This has resulted in increased waiting list and waiting times. To address this two additional PDS Link Workers were recruited and are now fully operational. Waiting list numbers are now reducing and in particular there is an improvement is waiting times. This has reduced from over one year to around 3 – 4 months.

4.6 **Care Co-ordination and 8 Pillar Model Community Support**

This refers to the stage of the dementia journey when people are living at home and supported to live independently and remain connected to their community, for as long as possible, as dementia progresses. This is aligned to Alzheimer Scotland 8 Pillars Model of Community Support, and when required care and support is co-ordinated by a care co-ordinator. A care co-ordinator can be a social worker, district nurse, community psychiatric nurse, Allied Health Professional or GP. The Programme hosted its 4th learning session in May 2021. This focused on care co-ordination, the different levels and duration of care co-ordination and local examples of care co-ordination in Inverclyde. A number of areas were identified where care co-ordination could be improved, e.g. improved communication, clearer roles and responsibilities and clearer pathways to services and supports, all of which are included in the Programme Action Plan.

4.7 **Alzheimer Scotland Advanced Dementia Practice Model (ADPM)**

Testing Alzheimer Scotland ADPM is a requirement of the Programme. This Model sets out to ensure palliative and end of life (PEOL) care and support needs for people living with advanced dementia are met, including the needs of their family and or carers. A working group has been established to agree how the ADPM is implemented and tested in Inverclyde. A Needs Based Approach has been agreed as a Framework to test and implement the ADPM in Inverclyde, see figure below.



Advancing dementia needs supported by their care co-ordinator. However where needs are not being met, their care co-ordinator can consider if input from the Advanced Dementia Specialist Forum (ADSF) is required. Currently the effectiveness and added value of the Forum is being tested and evaluated.

Advanced Dementia Specialist Forum

The purpose of the Forum is to ensure the best possible experience of care and support for people with advanced dementia, including their family and/or carers. The Forum brings together multi-disciplinary and multi-agency expertise, including health, social care and third sector partners. It aims to facilitate discussion that leads to recommendations which support the effective and co-ordinated delivery of appropriate care and supports that takes account of the preferences of individual and their carers. The first ADSF was held on the 4th June, 2021. Two cases were presented, discussed and recommendations were made. Feedback from Forum members and practitioners presenting the case was positive. The multi-disciplinary input and gaining insight from a wide variety of services and supports was valued. Duplication of existing multi-disciplinary meetings was a concern, however this was not the case as the Forum allowed more time for detailed reflection (see section 8.1 for full report). Subsequent Forum monthly meetings have been arranged.

Palliative and End of Life Identification Tools

It is recognised that dementia gradually deteriorates over a longer period of time and often PEOL care and support needs are not recognised until end of life stage. It is therefore important that this stage is recognised to ensure appropriate PEOL care and support is in place. A short life working group has been arranged to progress the identification tool or a basket of tools that can be used in Inverclyde.

4.8 **Workforce Development**

The ambition for Inverclyde is to have in place a sustainable approach to dementia workforce development. The programme is working to ensure the workforce, 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 will include health, social care, third sector, community groups, volunteers, housing and care home staff. To achieve this a 2 day per week dementia training co-ordinator position will be recruited for 18 months, using earmarked reserve for dementia work in Inverclyde. The post holder will co-ordinate, deliver and facilitate training capacity within the existing workforce.

4.9 **Self-management leaflet**

A self-management leaflet has been developed for people newly diagnosed with dementia. Inverclyde Dementia Reference Group informed its development. This provides brief information and contact details for a numbers of health, social care and third sector supports available in Inverclyde, (see section 8.2). Plans are in place to review and evaluate the leaflet with service users. The leaflet will also be available online and provide direct links to information and service.

4.10 **Self-management App**

A requirement for the Programme is to explore digital solutions to support self-management. A short life working group has been established to develop a self-management app and symptom tracker for people living with dementia. This work is being done in collaboration with the GGC eHealth team and the Digital Health & Care Innovation Centre (DHI). It is in the early stage of development and will be informed and tested by people living with dementia.

4.11 **Clearer Roles and Responsibilities and Service Pathways**

This has been raised on a number of occasions including the last learning session. Discussions with stakeholders are underway to agree how this can be improved.

4.12 **Dementia and Housing**

Discussions are underway to explore local implementation of the Housing and Dementia Framework. The Framework provides the tools for the housing sector to build on existing good practice and help people living with dementia, their families and carers to live in homes which

have enabling environments and help them achieve the outcomes that matter most to them. Dementia awareness training, delivered by Alzheimer Scotland Dementia Advisor, is planned within local sheltered housing. Early housing discussion by the PDS Link Workers is being explored.

4.13 **Allied Health Professional (AHP) contribution**

AHPs have a key role in supporting people living with dementia and their family and/or carers. Discussions are underway to explore and enhance the AHP contribution to an integrated and co-ordinated approach as outlined in the Alzheimer Scotland AHP framework, Connecting People, Connecting Support.

4.14 **Anticipatory Care Planning (ACP)**

There is currently improvement work underway across Inverclyde relating to Anticipatory Care Planning. Part of this will ensure the completion and review of ACP for everyone with a dementia diagnosis. Team Lead from Older Person's Mental Health team is currently co-ordinating ACP training and identifying and agreeing a process for recording and sharing the ACP with other HSCP services.

4.15 **Dementia Friendly and Enabled Community**

Dementia friendly communities and culture was a priority identified at the Programme launch event. The scope of the initial improvement idea has widened in the context of the Covid-19 pandemic which has led to an increase in the difficulties and challenges experienced by individuals living with dementia. This work links to Commitment 11 of the Scottish Government Dementia and Covid-19 National Action Plan:

> **COMMITMENT 11:** Working with local health and social care partnerships and the third sector, community groups and businesses we will support and enhance local dementia-enabled communities and reduce social isolation and loneliness, as part of our shared action to strengthen and recover resilience in our communities.

Using earmarked reserve for dementia work in Inverclyde, processes are underway to commission an external organisation to take this work forward. This will build on previous Inverclyde Dementia Friendly work.

4.16 **Measurement Plan and Evaluation**

The Programme is quality improvement driven and requires measurement of impact. A Programme data sub-group is meeting in July 2021 to identify and agree a Programme measurement plan. This data will support Programme evaluation requirements. The Scottish Government is in the process of commissioning an external company to carry out a robust evaluation of the Programme.

4.17 **Sharing Programme Learning**

A requirement of the Programme is to share learning across NHS Greater Glasgow and Clyde and Scotland. Programme updates are provided at national events e.g. National Post Diagnostic Support Leads meeting. Learning so far has been shared through existing networks across NHS GGC area. The Programme is now in early discussion stages to arrange an end of Programme shared learning session. This will involve national and local stakeholders including people living with dementia and carers.

4.18 **Sustainability**

Discussions are planned with stakeholders to consider the sustainability of the Programme priorities at the end of the Inverclyde Dementia Care Co-ordination Programme in March 2022.

5.0 PROPOSALS

5.1 The HSCP are asked to note the contents of this paper, Programme achievements and action planning until its conclusion in March 2022.

6.0 IMPLICATIONS

Finance

6.1 Financial Implications:

Cost Centre	Budget Heading	Budget Years	Proposed Spend this Report £000	Virement From	Other Comments

Annually Recurring Costs/ (Savings)

Cost Centre	Budget Heading	With Effect from	Annual Net Impact £000	Virement From (If Applicable)	Other Comments
Dementia earmarked reserve					Dementia training co-ordinator - approximately £26,245 for salary and other costs for 18 months. Dementia Friendly and Enabled Community project - approximately £62,000 for salary and other costs for 18 months.

Legal

6.2 No implications

Human Resources

6.3 Agree job description and person specification for the Dementia Training Co-ordinator position which will be subject to HR job evaluation process to determine appropriate Grade.

Equalities

6.4 Has an Equality Impact Assessment been carried out?

	YES
X	NO -

Repopulation

6.5 No implications

7.0 CONSULTATIONS

7.1 Involving stakeholders has been central throughout the Programme. 92 stakeholders attended the Programme launch event in September 2019, including people living with dementia, carers and representatives from local and national organisations. Priority areas were identified and agreed and informed the overall Programme action plan. Shared learning, progress updates, improvement ideas and action planning were generated through Learning Sessions.

Arrangements were agreed to involve Inverclyde Dementia Reference Group (DRG). The DRG have been instrumental in informing and supporting areas of work, e.g. participated in local stakeholder engagement work commissioned by HIS; development of a self-management leaflet; contributed to the design of a single quality question for the PDS Service; shared their experiences during the first wave of the pandemic, which was used to inform national policy.

8.0 LIST OF BACKGROUND PAPERS

8.1 **Inverclyde Dementia Care Coordination Programme Update Report: First Advanced Dementia Specialist Forum**

Report ADSF June 2021.docx

8.2 **Inverclyde HSCP Self-Management Leaflet**

Dementia Z-fold 4C.pdf