

Driving Improvements in **Specialist Dementia Care**

Dementia Specialist Improvement Leads (DSILs)
improving care and support for people with
dementia, their families and carers in Scotland



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in Specialist Dementia Care 2020**
Designed by the NES Design Team

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A celebration

This report celebrates the achievements of the 109 graduates who have qualified in three cohorts from the NHS Education for Scotland (NES) Dementia Specialist Improvement Lead (DSIL) programme.

The DSIL programme is a bespoke, 18-month development initiative that began in 2014, set at the Expertise level of the Promoting Excellence knowledge and skills framework.

The DSIL programme grew out of reports that highlighted a need to invest in and develop specialist care for people living with dementia, their families and carers who receive support and treatment from NHS mental health services and care homes. It recognised the potential of those working in specialist dementia settings to drive forward improvements in people's care and support, and contribute to the transformation of specialist dementia care in Scotland.

Initially targeted at mental health nurses, the programme was broadened to include a range of staff from health and social care. Its aims were to further develop participants' knowledge and skills in a range of specialist areas; to develop their skills in leadership, change management, practice development and quality improvement; and to enhance their ability to work in partnership and

facilitate learning in others to support improvements in dementia practice.

Based on in-depth interviews with DSIL programme participants, this publication is aimed at all stakeholders with an interest in improving specialist dementia care, including people living with dementia, their families and carers.

The report showcases the impact of the DSIL programme in four key areas: participants' own development, and their role in developing others, working with others, and supporting people with dementia, their families and carers. As well as exploring those four themes, the publication includes a series of case studies that provide illustrative examples of the impact of the DSIL role.

The report concludes with reflections gathered from the team involved in the delivery of the programme, who consider participants' achievements and the impact DSILs have had on the experience of and outcomes for those who require care and support in specialist dementia settings.

The learning demonstrated in this report can be used to inform the development of frontline staff and their managers, and policy and planning leaders in health boards and health and social care partnerships in Scotland.

NES Dementia Specialist Improvement Leads development programme

Change project

National training programmes at Expertise Level of Promoting Excellence

- Supporting change Facilitation skills
- Meeting the complex physical healthcare needs of people with dementia
- Pharmacological care of people with dementia
- Essentials in psychological care for people with dementia
- Palliative and end of life care in dementia
- Masterclasses

Optional learning opportunities

Leadership and personal development

- Learning log
- Practice based facilitated learning and development groups
- Peer support
- Networking and online community of practice
- Other activities
- Support from NES team



Working **as a DSIL**

Since its launch in 2014, professionals from a range of health and social care backgrounds have completed the DSIL programme. What they have found is not just an education programme that helps them improve their work with their teams and people living with dementia, their families and carers, but also a transformational and, for some, career-changing experience.

As described in the introduction, various themes emerged from conversations with those who have been through the DSIL experience. This section considers those themes in greater detail. It features professionals who have been through the DSIL programme talking about how it has given them the courage, confidence and capability to change and enable others to change.

DSILs developing themselves

Describing how the DSIL experience changes the way people think and act is common among those who have taken the programme. The starting point for this is the fundamental change in perception and belief that the DSIL programme inspires.

Passionate about dementia care

Yvonne Manson is operations dementia manager for Balhousie Care Group and was a participant in cohort 3 of the DSIL programme. She found that the programme did not so much inspire her to do more, but rather to rein in and focus her enthusiasm – in a positive way.

‘I’m really passionate about dementia care, so I tend to run off and try and do a million things at once,’ Yvonne says. ‘I cover 25 care homes across Scotland, so that’s a lot of running around. But the DSIL programme has shown me that slowing down, reducing the pace, actually helps us see things more clearly and act more positively.’

With such a wide-ranging remit, Yvonne also finds that speaking to people – sometimes large groups of people – is very much part of the day job, and the programme has helped in that sphere too.

‘I’m often at conferences where I’ve got to get up and speak to people. The programme helps because it involved a lot of speaking in front of people, so I got the practice. But the less tangible element is the confidence it gives – I feel much more confident now in what I believe and what I say.’



Big impact

The programme offers participants access to a range of tools and techniques that can support them in achieving positive change back in their workplaces. One such tool is appreciative inquiry, which has had a big impact on Karen Spiers, a senior charge nurse in an older adult dementia assessment unit in NHS Lanarkshire and one of the DSIL pioneers from cohort 1.

‘I’ve been in a leadership role for a number of years now so have become quite experienced and knowledgeable in areas like quality improvement,’ Karen says. ‘But I had never used appreciative inquiry as a tool for change.’

Appreciative inquiry is a strengths-based positive approach to leadership development and organisational change. It is quite different from many improvement approaches that tend to focus on deficits and problems.

‘Using the appreciative inquiry approach with a group of staff, I found that it helped us define what it was we wanted to change – not



change because it was wrong, but because staff realised through appreciative inquiry that they wanted to make it better,’ Karen says. ‘It’s been the foundation for us making some really successful changes in the ward.’

Exploring change

Nicola Hurst, a community mental health nurse in NHS Fife, found that the DSIL programme encouraged her to explore change through the experience of others.

‘I found out what my fellow programme participants and those who have gone through the programme before are doing and what achievements they’ve already gained or are looking to gain,’ Nicola says. ‘I’ve been able to take that back to my own team in Fife, using appreciative inquiry to drive forward change by looking at what we’re doing well and deciding how we can build on that.’





The DSIL programme is showing me that slowing down, reducing the pace, actually helps us see things more clearly

Learning about learning

The most positive aspects of the programme for Thomas Bohlke, who now works as an inspector for the Care Inspectorate, were two-fold. First, it provided a wealth of up-to-date knowledge on various aspects of dementia care from experts in the field. And second, it offered the opportunity to exchange information, knowledge and ideas with other practitioners.

‘I was most interested in learning about learning,’ Thomas says. ‘The programme looked at how people can learn, which doesn’t need to take place in a classroom. There are other, more flexible options, like experiential or immersive learning – we learned about this through props to simulate and increase awareness of what people living with dementia experience daily – accessing media and educational resources, varying delivery methods and using action learning.’

‘And meeting and working with practitioners in acute services, NHS community services and care homes gave each of us a chance to discuss and work out how we would facilitate knowledge transfer back in our work environments.’

Thomas, who trained as a nurse in Germany before moving to Scotland, changed jobs during the programme. He was the first Admiral Nurse in Scotland for a group of care homes but moved on to the Care Inspectorate.

‘As an Admiral Nurse, it was easy to apply the learning from the programme in practice,’ he says. ‘I used experiential learning methods in

care homes and encouraged staff to look at how to provide better care for people in the late stages of dementia through approaches like Namaste care.

‘My Care Inspectorate role, which of course includes a scrutiny function, also allows me to advise services on best practice in dementia care,’ says Thomas. ‘So, I continue to draw on my previous learning, including the DSIL programme, and stay in touch with new developments through things like attending NES masterclasses.’



DSILs developing others

Common ground

Kate MacKay's work straddles social care, education and health care. She is a college health and social care lecturer in Lanarkshire and also works as a nurse advisor for quality for Northcare (Scotland). Finding a DSIL programme-inspired project that would meet the needs of colleagues as diverse as students on the Care and Administrative Practice Higher National Certificate course at the college and senior managers and clinicians in the care homes might have been tricky. But the common ground she has found is the need for all people to be able truly to empathise with the experiences of older people with dementia.

Her project is called Face2Face with Dementia and it explores empathy through experiential learning. Support from the care home organisation enabled her to purchase simulation suits, which allow the user the experience of various deficits associated with older age.

'There are educational experiences out there that try to simulate dementia so that people can get the real experience as much as possible, but the programmes don't simulate dementia and older age together,' Kate explains. 'I wanted people to get the experience of cognitive difficulties, but alongside the challenges of a failing body.'

The suits come in a range of pieces that when worn simulate the effects of, for instance, eyesight, hearing, joint and walking problems. Kate has also created a 'white noise' resource for mp3 players. The aim is to help users experience not only physical and sensory issues commonly experienced by older people, but also try to get a sense of what it must be like to have cognitive difficulties as well.



'I think it's an ideal approach for people to have experience of what it might feel like to be older and have dementia,' she says. 'We've added sounds on the mp3 players I've taken from my own experience of being in the care home units, where I can see the residents trying to make sense of what they're hearing.'

'Maybe they hear someone shout across the room. They'll hear the vacuum cleaner. They'll hear the phone ringing. There's maybe someone in visiting with a baby, and the baby's crying. Someone else might be in with a dog, and the dog's barking. Staff are in the kitchen and the dishwasher is going and the ventilation system is humming. This noise, which residents hear commonly, is what I've recreated in the audio and is what staff and students hear when they take part in the simulation.'

The results have been little short of transformational in terms of people's understanding of empathy.

‘I can’t even describe how successful it’s been so far,’ Kate says. ‘When we ask participants before the training if they believe that people with dementia are receiving empathic care, around 90% say yes. After the training, only one person of the 60 or so we’ve trained so far has said yes. They believed they had been delivering care with empathy but realised actually they didn’t have a full understanding of what the person’s life might truly be like.’

The experience can be profound for trainees.

‘We’ve had a couple of people who have taken their headphones and their simulation goggles off and the tears are running down their face,’ Kate says. ‘It has a huge emotional impact, and I always make sure I have a colleague with me so we can do proper debriefings with people and help them understand the positives of the experience they’ve just had in terms of them moving forward.’



There’s a lot of people in the community who want more knowledge about dementia

Cascading benefits

Nicola Hurst, the community mental health nurse from NHS Fife, recognises that being on the DSIL programme presents a lot of privileges to the individual, but the responsibility then is to cascade the benefits through the team and service.

‘I was going to development meetings and we were discussing our vision for change and improvement in our service,’ she recalls. ‘I saw the potential to apply some of my learning from the DSIL programme.’

Using the appreciative inquiry approach, Nicola brought a project focus to the regular meetings, starting with some work on creating a discharge pathway for families. She found that her colleagues were only too keen to get involved.

‘Giving the meetings a project focus, a theme, has really helped,’ she says. ‘We look at how we can make changes to our service in a positive way. Everyone is quite excited about it, so we all really look forward to the meetings.’

There have been knock-on effects in Nicola’s own team, who also seem to have caught an enthusiasm for improvement. Discussions using appreciative inquiry have helped to improve their confidence and heighten their enthusiasm, so much so that Nicola finds she is now able to delegate much more effectively.

‘Delegation was a big problem for me, and I would often decide just to do things myself,’ Nicola says. ‘But I’ve found that delegating to other people and seeing how excited they become about taking on a new role is good for me, and for them. Everyone in the team has grown in confidence. They all want to take jobs on, so it’s been really good for our team.’

Nicola also feels the team’s horizons have expanded. ‘The appreciative inquiry approach has brought everybody out of their shell, and they’re looking at things in a wider way rather than just maybe thinking about their specific job descriptions,’ she says. ‘Our joint ethos has been strengthened.’



Invaluable resource

Part of Yvonne Manson's role as operations dementia manager for Balhousie Care Group is to oversee a dementia ambassador programme that involves just over 100 care staff, nurses, domestic staff and others in the organisation. She found the tools and techniques she learned about on the DSIL programme provided invaluable resources in developing and delivering the ambassador programme.

'I often said to the ambassadors that I had a DSIL course coming up on something like palliative care or complex care and suggested that when I came back, we would go over what I'd done,' Yvonne explains. 'We were then able to design something around what I'd learnt, or just hone something we were already doing and tighten it up or change it slightly. And when I came back, of course, I was pretty excited because of what I'd been learning, so the enthusiasm seemed to rub off!'

Huge role

District nurses have a huge role in supporting people with dementia. Karen Burns, district nurse team leader in NHS Grampian, found that her colleagues quickly realised how her participation in the DSIL programme could help them deliver better care.

'When I started on the programme and fed back what I had been learning and what I was hearing from other people who were involved in the dementia field, my colleagues were very interested, asking questions, wanting to know more, and asking if there were going to be any teaching sessions for them,' Karen says. 'There's a lot of people in the community who want more knowledge about dementia, which is great because it means that I've got something I can bring to them. So many people come to me – I hadn't realised how much people wanted to know.'

The plan at the moment is that all team members will be trained to the skilled level of the Promoting Excellence framework, with Karen developing the course.

'I want district nurses to engage with it and reach the same level, so they've all got that skilled-level knowledge and skills,' she says. 'And if they want to develop on that, there are opportunities through, for instance, NES masterclasses that will take them to the enhanced level.'

'But having everyone with skilled-level knowledge means they would be able to recognise potentially important changes in people when they visit them in their homes, which could trigger thoughts like, maybe we should look at discussing medications, hydration or nutrition, rather than thinking that the person's dementia may be advancing. That's the aim.'

DSILs working with others

Networking opportunities

Kate Mackay, the health and social care lecturer who also works as a nurse advisor for quality for Northcare (Scotland), is full of enthusiasm for the benefits of the DSIL programme. But one of the biggest advantages, she feels, is the opportunity it offers to network and work with other professionals.

‘The DSIL programme is amazing for the networking opportunities with other professionals,’ she says. ‘We have geographical groups for DSILs, and I’m the only person with an education background in my group – there’s one who is a unit manager in a care home and the others are in NHS posts.’

Kate finds the camaraderie that has developed in the DSIL group is not only enjoyable

and supportive but is also leading to very tangible benefits at service level.

‘One of the DSILs in the group who works in the NHS was struggling with his project for funding reasons,’ she explains. ‘At the time, I was working with a group of junior students in the college who were studying citizenship and who had decided to raise some money for a good cause. We donated the money to my DSIL colleague’s project, so he was able to open a special room for families to be with their relatives at the end stage of their dementia journey. It’s great – the families are benefitting and inter-professional working is being encouraged. And the students were invited along to the opening of the rooms, which gave them a big thrill.’



My own learning and knowledge is being shared with others in my area

Opening doors

Karen Burns, district nurse team leader in NHS Grampian, has found the DSIL programme has opened doors to working with colleagues in other professions. Her geographical group contains a mix of expertise that provides a rich resource she can access for support and advice.

‘It’s been so good to speak to people from different health boards,’ she says. ‘Several are community mental health nurses or mental health staff from specialist units, it’s given me a clearer understanding of what happens to people with dementia who move from the community into mental health care.

‘But my own learning and knowledge is also being shared with others in my area,’ she continues. ‘We’re looking very closely at post-diagnostic support in Aberdeen at the moment. The service is being re-designed, which involves a lot of teams – physios, occupational therapists, care management – a lot of different disciplines are at the table trying to figure out the best way of moving forwards so we’re providing the right service to those who are entitled to it. And I find that as a DSIL, I’m able to contribute very helpfully to that process, and people listen when I do.’

DSILs supporting people living with dementia

The DSIL programme is certainly about supporting professionals to develop their perceptions, knowledge and skills. But the bottom line is that it first and foremost is about

making life better for people living with dementia, their families and carers. So what impact are DSILs having when they return to their workplaces?

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We hope people will feel much more supported and be able to access the appropriate help at the right time

Value of evaluation

Nicola Hurst, the community mental health nurse from NHS Fife, recognised early that changes in how services are being delivered need to be evaluated to prove their effectiveness.

‘Evaluations are a big part for me,’ she says. ‘Previously, I would tend to run off and do a project without thinking about how I’d evidence the impact it’s having – what has changed as a result of it? How has it helped improve outcomes for the person?’

Nicola believes that a lot of potentially very valuable projects flounder because of a lack of attention to evaluation.

‘The project leaders maybe don’t think about the gathering-evidence part sufficiently right at the start of the project,’ she says. ‘Appreciative inquiry has given me a really helpful approach for examining outcomes more robustly.

‘If we as a team feel we’re really good at something, appreciative inquiry challenges us to identify why we’re really good,’ she continues. ‘It makes us define the outcomes for the person, which in turn asks us to consider how we’re going to evidence it. We need that depth of evaluation so we can then say with confidence that we should be taking a change forward in our service.’

The appreciative inquiry approach enabled Nicola and her colleagues to identify a gap in current services around support for carers after people had been discharged from the community mental health service.

‘We sent appreciative-inquiry based questionnaires to professionals and families/ carers to establish what they thought we did well in relation to post-discharge support, what knowledge they had and lacked, and what support they did and didn’t have,’ Nicola says.

‘We saw that families and carers needed a lot of support post-discharge and often weren’t sure about where to go for help – there were phone calls that could maybe have been better directed to more appropriate support, for example.’

Nicola was working with a student nurse at the time and asked him to review examples of post-discharge pathways that the service could consider and perhaps adopt. Regular meetings with colleagues also produced ideas for how a pathway might look.

What is emerging is a one-page laminate guidance that signposts carers to exactly where they should go for support on whatever issue they have.

We’re making the pathway very simple and easy to follow,’ Nicola says. ‘It’s something they’ll be able to stick on the door of the

fridge and will direct them to the exact place they should be, including the phone number for emergency services.’

The team is now working on draft three of the pathway and the progress made so far is giving team members a real sense of achievement.

‘I think we feel more confident in discharging patients and carers from the CPN service now because we know exactly what information we need to give them,’ Nicola says. ‘We hope people will feel much more supported and be able to access the appropriate help at the right time. They will know that even if they don’t have somebody immediately involved at the time, there’s a phone number they can contact to enable them to continue to live well. And it will help them feel in control – that’s a major plus.’

Monitoring medication

Yvonne Manson, operations dementia manager for Balhousie Care Group, is sensitive to the need to regularly monitor use of antipsychotic medication across the organisation’s care homes. The DSIL pharmacological course gave her an opportunity to consider this issue in even greater detail.

‘The pharmacological course is really quite intensive, but it covers a hugely important issue in care of people with dementia,’ she says.

When Yvonne was taking part in a DSIL course, she would always think about how she could take ideas and information back to support the staff. She recalls one particular experience when one of the members of her DSIL group was talking about the numbers needed to treat – the number of patients you need to treat to prevent one additional bad outcome – and the numbers needed to harm, which basically is how many people need to be exposed to a risk factor over a specific period to cause harm to one person who otherwise would not have been harmed.

‘I used a number of different exercises with staff to help them explore and understand some of the unwanted effects of antipsychotic medication, and consider what they might want for themselves,’ she says. ‘It made people start to think, wait a minute, we shouldn’t go straight to medication if we haven’t tried x, y or z first – maybe we should try other strategies, like psychological interventions.’

Yvonne took her experiences back to her organisation and started a debate on how psychological interventions might be better options for residents.

‘On World Patient Safety Day this year, I checked prescriptions of antipsychotic medications over the previous year and compared them to the year before that,’ she says. ‘Across the 25 homes, we’ve seen an average decrease of 8.5% – that might not seem huge, but I think it is a pretty impressive start. It shows that people are now thinking differently on the use of medication and providing alternative approaches.’

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We've changed the practice in the ward and the way people think about falls

Change leadership focus

Gillian Gibson, lead nurse for the older adult community mental health services in NHS Fife, found the change leadership focus of the DSIL programme particularly valuable in her then role as a senior charge nurse in a specialist dementia unit.

‘I took a lot away from the change management leadership discussions,’ she says. ‘I was able to go back to the ward and use it to inform practice. So, when changes needed to be made, it wasn’t a case of “let’s just make a change”. We were able to take a more structured approach, using techniques like the plan, do, study, act cycles and other improvement methodologies. It helped us deliver quick but substantial results that we could then roll out to other areas.’

The work of Gillian and her colleagues was recognised formally when they were finalists in the best hospital-care initiative category in the Scottish Dementia Awards. They were also highly recommended in the annual awards of the Mental Health Nursing Forum for a holistic adult assessment tool they had developed. More recognition came from the Scottish Dementia Awards for Gillian’s work in education within the board area.

‘I developed a Promoting Excellence learning plan for the health and social care partnership that looked at identifying the learning needs of staff at all levels,’ she says. ‘This prompted us to set up a working group looking at education, working really closely with the Alzheimer Scotland nurse consultant in NHS Fife.’

The group has mapped out all the dementia-specific training currently on offer and which might be available in future and is now looking to create an education strategy specifically for dementia in Fife.

‘Facilitating training isn’t easy, but the DSIL programme has really helped me to understand better how to meet people’s needs,’ Gillian says. ‘The education programme had started before I did the DSIL programme, but we’ve now reviewed it, revised it and enhanced it as we’ve gone along. It’s now completely different to what we had originally, and the service improvement projects that have come out of it are evaluating really well.’



Falls concerns

When Karen Spiers was appointed senior charge nurse in an older adult dementia assessment unit, she had some concerns about the incidence of falls in the ward and an environment that may not have been fully supporting patients' independence.

Wards like Karen's can be considered high-risk for patients falling. The patients' ages and diagnoses, long-term physical and cognitive problems, and factors such as their nutritional state, medications and the fact that they are in an environment they are not familiar with make them vulnerable.

'Because of these factors, I saw that falls were actually a great indicator of where we were,' Karen says. 'I started taking measurements and could see that the ward environment needed to change to reduce risks to patients.'

Karen concedes that a completely fall-free environment in a hospital setting is probably not possible, so her initial aim was to prevent and reduce falling, rather than eliminate it completely.

The aetiology of falling is very complex, and Karen understood that she would need to look for solutions beyond the simple mechanics of walking.

'I could see that there weren't actually many places where patients could rest if they were up and walking about, so we put in rest points – just chairs at various part of the ward where patients could sit and rest,' she says. 'But we then started looking at other elements, such as patients' bowel and urine habits and whether they had had any infections, so we got ahead of that being a problem. Hydration in the ward improved – we introduced activities like film nights that we built fluid and nutritional elements into.'

Lighting in the ward was reviewed to make sure it was sufficient, and Karen and her team looked at medication use and realised prescriptions increased in the evenings, associated with



some patients' levels of agitation and anxiety rising at that time of the day.

'We changed staff rosters to ensure staffing levels in the afternoons were sufficient to meet patients' needs, to spend time with patients to try and reduce the build up of agitation and anxiety,' she says. 'We introduced more activities and one-to-one sessions using low-intensity psychological interventions, and night staff were trained on how to engage with people who are getting up and out of bed.'

All of this effort has contributed to a month-on-month decline in falls since January 2018. And it was recognised by NHS Lanarkshire in an award for the team for making an outstanding contribution as a clinical team and going the extra mile to improve patient care.

'This month, we've had one fall,' Karen says. 'We've changed the practice in the ward and the way people think about falls. These things don't happen just because you tell staff to do something – they happen because of a cultural shift in our ward towards working and thinking in a more patient-centred way.'

What being a DSIL means



Kate MacKay, health and social care lecturer, and nurse advisor for quality for Northcare (Scotland)

The DSIL programme has given me a really good platform for influencing change – to develop as a change agent within the dementia world – and the DSIL title has probably enabled me to negotiate better. The care home organisation I work for operates in an evidence-based way, so if you can provide evidence of where you can influence change, the company will provide the resources. I think being a graduate of the DSIL programme just gives me a bit more credence and greater leverage when it comes to those kinds of negotiations.

I've been on lots of train-the-trainer experiences, but the DSIL programme was the most profound for me. This was the one that made me feel I could really make a difference. My goal is to improve the life of people living with dementia, but I'm not providing direct care. I needed to look at how I could improve care through education of others. My roles in the college and the care home organisation enable me to do just that.



Karen Burns, district nurse team leader, NHS Grampian

Being a district nurse, I'm general trained. Previously, I didn't have much knowledge about mental health at all. Dementia care is increasing in the community, and we need more knowledge about how to support people. It doesn't seem that long ago that people with dementia would just go into hospital for specialist treatment, but the whole thrust of health and social care is now community-based, and that is where people need support.

The DSIL programme has provided me with a foundation for developing a service in the community for people living with dementia.

I've been able to develop a new service, enhance what's already there, and develop a new teaching system in the community, which I'm hoping to run across Aberdeen city.

It wasn't something I thought was going to come out of the DSIL programme, to be honest. I thought it would be more of a personal experience; sure, I would be able to share my new knowledge with colleagues, but I would be the main beneficiary. But the programme has opened the door to this wider opportunity to develop a new kind of service that will be community-based.



Wullie McLoughlan, charge nurse, older adult dementia assessment unit, NHS Lanarkshire

I've only been working in dementia care for the past three years. My background was adult admission. After a year and half working in the dementia assessment unit, Karen [Spiers, the senior charge nurse on Wullie's ward] put me forward for the DSIL programme. And it was a lightbulb moment for me.

In an admissions ward, it's all about treating people with medication and helping them attain a level at which they're well enough to leave the ward. In the dementia assessment unit, it's not about medication. The programme gave me the confidence to have a look at my practice and change the way I'd worked for the previous 25 years. I have a totally different way of looking at things now.

I wouldn't say I'm the most studious person in the world, but I can take it in, and the way the DSIL programme is structured has really helped me bring things back to my practice and educate other people. Karen and I have improved other people's practice, not just our own, because we always bring new knowledge and ideas back to the ward.



Nicola Hurst, community mental health nurse, NHS Fife

The DSIL programme has given me the confidence to be able to ask, 'Why don't we try this?', and to ask people for their opinions without being frightened of what they might say. It's taught me how to feel and respond when somebody says, 'That's not a good idea, you're never going to go far with that, this is the way we've always done it.' It's not about confronting people, it's about inspiring them to think in a different way. That's what the DSIL programme has done for me.

The programme has also made me much more aware of the national picture – not just what's happening in other boards, but the national policy drivers, strategies and legislation we can use to push for better services. That's our foundation, and that's what we should be striving to deliver. We need to take it back to the people who matter, the ones who are going through this journey.



Gillian Gibson, lead nurse for older adult community mental health services, NHS Fife

It all started when a colleague and I were having a discussion about what training was available for our staff to help them develop the knowledge and skills they need to work with people living with dementia. We then spoke to colleagues at NES about the Promoting Excellence framework and ended up taking away and adapting a NES programme to bring people to the skilled level, creating a training programme for mental health services in Fife.

I really enjoyed doing that. So, when the opportunity of the DSIL programme came along, I put myself forward because of the educational aspect. But it turned out to be much, much more than that. I found that it really widened my professional outlook and perspective. I had been quite insular in outlook, not seeing beyond NHS Fife. The programme enabled me to look at things on a more national level and in other boards and organisations.

That's where the networking element is so valuable. It was hugely beneficial to network with people from other boards, sectors and disciplines. It not only provided an opportunity to share good practice and learn from other people, but I was able to bring things back to my board and managers and say, this is what's happening elsewhere.

I was promoted about five or six months after graduating from the programme, and I don't think that's a coincidence. The programme was absolutely instrumental in my promotion – it gave me that wider outlook and strategic perspective which, combined with the changes I had introduced while on the course and after, put me in a very strong position.

I was delighted to be invited to assist in facilitation with cohort 3 by the project leads. That keeps my hand in on what's happening nationally and strengthens the working bond with the programme facilitators. And it gives me the chance to ensure the new cohort are as enthusiastic and motivated as we were.



Karen Spiers, senior charge nurse, older adult dementia assessment unit, NHS Lanarkshire

As the first cohort, we were kind of the guinea pigs for the programme. We were always being asked, is it beneficial, is it delivering new material, is it all relevant? The programme team listened to what we said. When we were asked to contribute to cohort 2, I saw changes in the programme that were based on the experiences of cohort 1.

The DSIL programme has done more than equip me with skills, competencies and confidence. It's also given me credibility. I absolutely feel credible in my role and feel able to advise and inform staff and share knowledge and experience with them. The programme was fantastic and came at the right time for me.



Gail McAdam, clinical trainer, Newcross Healthcare

Participating in the DSIL programme has broadened my knowledge and experience in all aspects of dementia care. Everything I've learnt on the training days I've been able to incorporate into my training, covering the whole of the Scotland.

I've been able to train nurses and carers who support people on their dementia journey in care homes and residential homes – they now have a better understanding and knowledge about complex health needs, stressed behaviours, polypharmacy and palliative care – and to upskill our trainers so they can deliver training to our workforce throughout the UK.



The programme has given me a whole new understanding and knowledge of dementia and the challenges it brings. It has also been great to network with the other DSILs – hearing about what they are doing in different settings is so inspiring.



Linda McDougal, NHS Dumfries and Galloway

I wasn't sure what to expect of the DSIL programme, although I was sure that I wanted to improve my own practice and that of the staff who worked on my ward to help us provide the best care we could.

I could see early on that all of us in the cohort were on a learning curve together. To meet likeminded individuals working in dementia care from all the different regions proved to be one of the most valuable and memorable experiences I've had. Hearing about the challenges my colleagues were facing and the successes they were having lifted my confidence – it gave me perspective on my own challenges in spreading learning, knowledge and good practice in my own ward and wider across the hospital.

The programme marries up learning and development with Promoting Excellence and Scotland's dementia strategy and enables us to integrate national and local objectives with our own personal and team objectives. Not all of the issues covered were new to me, but it allowed me to think differently about the care I provide and how I enable others to provide care.





Rachel MacLeod, dementia trainer, NHS Ayrshire and Arran

The DSIL programme has made me think more outside the box about delivery of training. It has given me different ways of providing the training, tapping into people's learning styles and delivering activities to suit. Also, it has helped me design and deliver training more

efficiently, providing it in bite-size chunks, which is a big bonus for staff who are time-pressed. The starting point for all training is the Charter of Rights for People with Dementia and their Carers in Scotland – DSIL is very much a rights-based programme, so the fit is perfect.



Mary Baxter, community mental health nurse, NHS Highland

I had worked with older-age clients, including people with dementia, for a number of years before starting the DSIL programme in 2018, so thought my knowledge of dementia was very good. I had been in a dementia-specific post since September 2016, using cognitive screening tools, giving post-diagnostic support to people and their carers and advising care home staff on stress/distressed behaviour. So, I wasn't sure if the DSIL course would actually teach me anything new.

I was wrong – I've learned a lot! All the content of the programme was researched-based and delivered by people with a great deal of experience in dementia care. It has changed how I work with people with dementia as I now have greater understanding of the disease process itself, both on psychological and physiological levels.

On another level, the DSIL course has given me greater awareness of what working within a team entails, especially when addressing

workplace challenges and introducing strategies to implement change. These are things I knew absolutely nothing about before. I've been able to use my new skills to improve communication within my team, listening actively to their views and opinions, and have shared some of the methodologies I've learned about with senior colleagues.

The programme has made me a more efficient professional. At all times I've felt supported, listened to and valued by all members of the DSIL team. Their wealth of knowledge and experience shines through.

Thank you!





DSILS **in action**

Following their participation in the education programme, DSILs have applied their learning in various settings, leading, inspiring and supporting others to bring change to how they support people with dementia, their families and carers.

In this section, through a series of five case studies, we hear first-hand and in more detail about the differences DSILs have made – about the challenges they have faced and how, equipped with new skills and confidence, they have overcome those challenges, leading the way towards improved support for people with dementia, their families and carers.

Case study 1

Making connections

After working with care homes and home carers, DSILs Anne Campbell and Lorraine Watson looked to other areas where they might support improvement in dementia care.

Good dementia care often depends on a chain of support. If one part of the chain is under heavy strain, it can threaten the entire system.

When community mental health nurses Anne Campbell and Lorraine Watson began the DSIL programme in 2016, they soon identified a potential weak point in dementia care locally and devised a training programme designed to strengthen it.

Four years on, the pair have won awards for their work and the training has expanded into other areas, including a prison and the police service.

Anne and Lorraine are senior nurse practitioners with NHS Highland's East and Mid Ross community mental health team.

Both have long experience of working with people with dementia but were keen to commit to the DSIL programme and discover what more they could learn.

The dementia training they devised as a consequence of DSIL focused initially on home carers – individuals employed by third-sector organisations to help meet the needs of people with dementia living at home.



‘The training came from a meeting where we identified that one of the barriers to good care was that the home carers didn’t really have the knowledge and skills they needed to support people with dementia who present with significant stress,’ says Lorraine.

‘The first training package we put together for them was a mixture of presentation,

interaction and DVDs, and the home carers were really committed to attending.’

She adds: ‘Without the DSIL programme we would really have struggled to know how to put the package together appropriately for the audience. The DSIL programme gave us the confidence and the skills.’



The DSIL programme gave us the confidence and the skills

Winning awards

Others heard about the training Anne and Lorraine had devised, and interest intensified after they were named winners in the 2018 Mental Health Nursing Forum Scotland awards for excellence – an ‘absolute highlight’ and an achievement that made them both ‘incredibly proud’, says Anne.

Although she and Lorraine were already delivering training to care homes, the subjects covered were expanded to include material covered by the DSIL programme. Then, approached by HMP Inverness, they drew up bespoke dementia training for prison officers facing growing numbers of older prisoners.

The police, too, were looking to raise awareness among officers of how to support people with dementia, so the two nurses devised a package for them as well.

Lorraine says: ‘It’s certainly improved communication with both those sectors. For example, police officers have our number now and they’re more willing to approach us if there’s something they’re not sure about. I don’t think that would have happened without the training.’

They feel another key outcome has been an increase in confidence among all those they have trained, which in turn helps care delivery. ‘For example,’ says Lorraine, ‘if somebody is presenting with distressed behaviour, they may be in pain or they may have an infection, and these are really basic needs. The home carers are now much more confident about approaching a GP to check these things out rather than struggling on with a person who is distressed. And that’s been really helpful.’

Anne adds: ‘One of the other things, a by-product of that increased confidence, is that we’re helping people to maintain their independence and stay in their own homes for longer. Care packages are not breaking down as much because those delivering the hands-on care are more skilled and more aware.’

As well as winning awards, Anne and Lorraine have been in demand as conference speakers, sharing insights into the success of the training they offer and its role in both improving care quality and, they feel, reducing the stigma around dementia.

And while they have been instrumental in helping to boost knowledge and skills in others, they both feel that they too have developed enormously since undertaking the DSIL programme.

‘If you had told me two years ago that I’d be standing up as a keynote speaker, I’d have laughed,’ says Lorraine. ‘My confidence has increased no end.’

Anne says: ‘For me, what we’ve done has re-energised my interest in research, looking at new approaches that are coming up. If you’re teaching you have to be aware of what’s out there, what’s current.’

To her surprise, she has also discovered she has a real passion for delivering learning. ‘I never thought I would say that,’ she adds, laughing.

Another attribute which Lorraine believes has come to the fore as a result of them putting together and delivering training packages is the ability to think outside the box. ‘We started off delivering training to home carers and care homes, but then you start to think who else can we support here? What else can we do?’

One outcome of that has been the ability to respond effectively to specific training needs, rather than aiming for a one-size-fits-all approach. Lorraine explains that if an agency is struggling with a difficult issue – someone with dementia is displaying disinhibited behaviour, say, and the home-care package is at risk of breaking down – she and Anne will devise a tailored 45-minute training session on that single topic. ‘And we can really support them to have the confidence to come to us to ask for advice,’ she says.



What we’ve done has re-energised my interest in research

Nurses first

A minor drawback with this willingness to respond in timely, supportive ways is that demand for training may outstrip capacity to deliver. ‘We’re nurses first, not trainers,’ says Lorraine. ‘So, we have to try and fit the training in around our caseloads and other liaison-type work we do because otherwise it could grow arms and legs and it would end up being unmanageable.’

But as they point out, the flipside is that whatever they can do to support others to deliver high-quality dementia care, so their own caseloads lighten a little.

‘What we’ve really wanted to do throughout is try and make life as comfortable as possible

for a person with dementia to remain as independent as possible and to remain in their own home, if that’s their wish,’ says Lorraine. ‘And we really hope the training is contributing towards that. That would be the big difference we would hope to make.’

The backing of their managers has been crucial to that ambition and indeed throughout Anne and Lorraine’s transition from expert nurses to expert nurses and trainers.

Anne says: ‘We were supported by our management to attend the DSIL programme and we’ve been well supported to get out and deliver training. I think in that way we’re very fortunate.’

Case study 2

Leading the way

Physiotherapist Claire Craig says the DSIL programme has helped her to look – and lead – beyond professional boundaries.

One of the many valuable takeaways from the DSIL programme is an increase in participants' confidence. And for Claire Craig, the first physiotherapist to undertake the programme, that became apparent in the teaching sessions she arranged once her DSIL training was complete.

Claire's role is unusual because she is one of a fairly small number of physiotherapists working in mental health. As lead physiotherapist for Inverclyde Health and Social Care Partnership, part of NHS Greater Glasgow and Clyde, she works with hospital inpatients and to date is the only physiotherapist DSIL in Scotland.

But taking on a leadership role in dementia care means cutting across professional boundaries, as well as seeking to educate and influence more junior staff and those in management roles. Claire has done both.

She was always confident presenting to or teaching fellow physiotherapists but as a DSIL she has now trained those outside her own profession as well – offering short, experiential education sessions to nursing assistants, for example.

Claire developed this bite-sized training – 45 minutes per session – for people to take away and apply immediately in their practice. Topics included the 'hand-under-hand' technique pioneered by US dementia trainer Teepa Snow, which helps carers to guide and assist a person with dementia.

'We went back after three months and did a retrospective analysis to see if people were using these things in practice,' Claire says. 'And what we're seeing is that they are. They've been able to reduce stress and distress



when supporting someone with eating and drinking, for example, by using the hand-under-hand technique.'

Since she ran the sessions for nursing assistants, psychologists, too, have asked Claire if she can teach them about hand-under-hand.

She has also helped to develop a family and carers' education group for those looking after someone with advanced dementia at home. Each group runs for seven weekly sessions and covers subjects such as nutrition, reducing the risk of falls, helping someone to move if their walking is deteriorating, and safety tips and technology that can support the carer. Various clinicians contribute to the group, including dieticians and psychologists, and evaluation has shown improvement in attendees' coping abilities, distress levels and how they feel after the sessions have ended.

For Claire, the DSIL programme is 'not about changing who you are but what you do'.

'It's about taking parts of your practice and building your confidence in them – having the strength to take these learning tools and put them into practice, not just in a local context but on a wider stage as well.'

Developing and delivering

In Claire's case, that means, for example, becoming the Chartered Society of Physiotherapy representative on the Alzheimer Scotland-led allied health professions national dementia forum. She also worked with an occupational therapy colleague to develop and deliver a Connecting People, Connecting Support launch event and strategic planning session for senior managers within Greater Glasgow and Clyde.

'It was a whole-day event and was based on appreciative inquiry, which was something I had done on both the DSIL programme and the national dementia group,' Claire explains.

Action learning

'Part of the DSIL programme involved action learning sets, which offered an opportunity for a small, local group – about eight of us – to come together in a group supervision arrangement. It was an opportunity to explore, to question, to look at our practice in detail,' says Claire. 'A chance to challenge and be challenged, and to critically evaluate the things we do.'

She adds: 'I think that was a really important part of the programme.'

From it, she took not only the capability to consider how her own practice might develop but also how best to encourage others to do likewise.

'The ability to listen and to help people find their own way forward without giving advice all the time, giving them the opportunity to explore through their own learning – that was something I did myself through the DSIL programme but I learnt how to help others to do it, too.'

'It's not always about telling people how to do things or what to do, but about empowering them to find it in themselves.'

Promoting physiotherapy and dementia care to senior staff, looking critically at service evaluation, assessing policies and papers, and contributing to the refresh of the Promoting Excellence dementia education framework – these are all initiatives Claire has taken on since completing the DSIL programme.

'I'm not sure I would have put myself forward for those things before,' she says.

While DSILs graduate with the skills and confidence to train others, the programme also encourages them to examine their own practice and to consider strengths and opportunities within it.

Clearly, Claire took much from the DSIL programme, but does she value one aspect of it over the others?

'The parts of the programme that had the biggest impact on me were the improvement methodology and evaluation sessions. I always wanted to show why the things we do and the changes we make are beneficial but in advanced dementia it can often be difficult to do that. And it can reduce your confidence in the change if people are challenging you on the benefits of it.'

'The impact of those sessions is that every improvement I've made since completing the DSIL programme has been evaluated.'

By using case studies, observational analyses, feedback, quotes and other evaluation tools she has proved that what she is doing is important.

'Now, when people challenge me on change, I can show them the evidence as to why that change is needed. So, my advice is, no matter what you do, evaluate it. It's only by doing this that we will change dementia services for the better.'

Case study 3

Let's look at this again

Karen Ritchie says becoming a DSIL taught her many things, not least that a fresh pair of eyes is sometimes what's needed to bring about real change.

A woman with dementia frequently wants to leave the home she shares with her husband, but he feels it is not safe for her to do so. Sometimes, in her confusion and determination to leave, she lashes out at him. The situation causes huge distress to both husband and wife.

'Why not let her leave and see what happens?', the husband is asked by a nurse-led team of skilled, dementia-trained mental health practitioners. The suggestion annoys him because he is sure his wife will come to harm, but he agrees, reluctantly, to try it.

A support worker visits and together they allow her to leave. When she reaches the front door, however, the woman merely looks outside and comes straight back in again.

'And that defused the situation,' says Karen Ritchie, senior charge nurse with NHS Lothian's Edinburgh-based rapid response team (RRT). 'It's so simple. But when people are in that situation and very stressed, they can find it difficult to make decisions about risk. It's about going in there and saying, "Right, let's take a moment and look at this again".'

The RRT, which has won a string of awards since its establishment in 2016, works with older people in mental health crisis in the community and tries to prevent admission to hospital. As a DSIL programme graduate, Karen has been able to apply to her role much of the learning she took from the course.

As well as instilling in her greater confidence in her leadership skills, the programme also encouraged her to be more creative

in her approach to dementia care and, where appropriate and safe, to take risks.

'Sometimes it's about saying, "Here's a fresh pair of eyes – what if we look at it this way?"; she says.

Another direct outcome of the programme, and one she helped develop alongside others from the first DSIL intake, was a full training package on dementia for people working in mental health.

The training tapped into existing expertise – staff on specialist dementia units, for example, as well as a specialist dementia pharmacist, and stress and distress trainers.

'It was about collating what was already out there,' says Karen. 'And as each of the different cohorts went through, they enhanced the training by using their new knowledge, so it was constantly being updated.'



Encouraging ideas

With the RRT, adaptability is key and from the outset Karen has been keen to foster a positive team culture where ideas and innovation are welcomed and not seen as destabilising.

‘I learnt a lot from the DSIL course about leadership – things about facilitating change, getting people on board and motivating them. Also, about getting the attitude right, the approach right, and the importance of being a can-do type of team. It’s about making sure we’re being as flexible as we can to allow people to stay at home for longer.’

Karen describes another couple on the team’s caseload where the wife’s dementia meant she was insistent about trying to leave the house to go to the pub or to play tennis. She appeared not to recognise her husband and he would become frustrated by her behaviour.

Applying what she had learnt on the DSIL programme about stress and distress in dementia, Karen considered the woman’s behaviour in relation to her timeline – how her current actions might relate to episodes in her past.

‘I was able to do an ad hoc training session with the husband that I would normally do with nurses, looking at where the lady’s reality was at that moment.’

‘So, by working through it with the husband and doing the timeline, we were able to identify she was probably thinking she was round about her thirties. Once I was able to show him, “This is what she thinks is happening, this is why she’s not recognising you”, he was able to adjust his approach to her accordingly. When he understood the reality for her at that particular moment, it helped take the stress out of the situation.’



*That’s the most important thing
– that people stay in an
environment they understand*

Understanding needs

Creative responses to dementia can help lift care and support to higher levels of quality. But understanding the complex physical health needs of people who may not be able to express them is clearly vital, too.

Karen says: ‘We get a lot of referrals from care homes where they say, “We can’t deal with this anymore, we want this person in hospital”.’

But the RRT is able to respond quickly with an assessment that helps the care home staff identify what may be the root cause of the person’s distress, rather than seeing the distressed behaviour in isolation. As a result, the resident is able to stay in their own home without transfer to hospital.

‘And that’s the most important thing – that people stay in an environment they understand. In our three years of service, the RRT has been able to change the pathway for older adults with mental ill health in Edinburgh.’

She cites the case of a man whose care home staff were struggling to support him and were pushing for hospital admission. By going into the home and seeing first-hand the man’s distress when staff were helping him to get out of bed, the RRT nurses quickly identified that some of the equipment being used to move him was causing him pain.

Karen says: ‘We like to go and do hands-on care and in this case that really helped resolve the problem quickly, just by getting more appropriate equipment and analgesia.’

‘A lot of what we do when working with people with dementia is around physical things that

just need to be identified or thought about a little more.’

Like other DSILs, Karen is totally committed to advancing dementia care – and is equally passionate about helping her team to improve the care they give.

‘I really believe that if you’re not person-centred towards your staff then you can’t provide person-centred care,’ she says.

She loves to see her team ‘shine in difficult circumstances’ – for example, when the RRT receives a referral and the odds seem stacked against maintaining the person’s placement but the team goes in and ‘does something a little bit different’.

Karen says: ‘I think the most rewarding part of my work here is supporting the staff and hearing them say, “We tried this – and it worked!”’

Case study 4

A team united

Maria Banks used learning from the DSIL programme to develop team members’ skills in delivering palliative care to people with dementia.

Delivering effective palliative care to people with advanced dementia who may be unable to express their needs and feelings demands exceptional knowledge and expertise from a team united in common purpose. Where appropriate, it also requires the close involvement of family members, so strong communication skills, sensitivity and partnership approaches are also necessary.

Senior charge nurse Maria Banks used the DSIL programme to initiate and inform a two-year project that sought to effect change in palliative and end-of-life care. She says the DSIL training provided her with a framework for the project and helped gain buy-in and support from management.



Maria is now based at NHS Greater Glasgow and Clyde's Royal Alexandra Hospital, but began the DSIL programme while working at a different hospital.

'When I took on the DSIL course, I started to look at palliative care in the widest sense – anticipatory care planning, ceilings of treatment, end of life care,' Maria says.

'I got a lot of learning from the DSIL programme, but in terms of application it became all about the palliative care project.'

The project was a significant piece of work and lasted two years. It began with a baseline survey of nursing, medical and allied health professional staff across two wards providing mental health care for older adults. The survey explored clinicians' understanding of palliative and end of life care, barriers to good care and training needs.

The responses fed into an action plan with 16 workstreams, which Maria admits now was probably excessive,

but perhaps reflected the scale of the task and the extent of gaps in training.

A key outcome from the survey and action plan was the appointment of two 'palliative resource' staff on each of the wards – highly motivated registered mental health nurses with experience of working with older people and a particular interest in quality improvement and end of life care.

There was no additional funding for the palliative resource nurses, but they were supported in other ways, Maria explains. 'Our service manager agreed that they could attend relevant foundation training. They would also get one day a month when the four of them would be rostered on a nine-to-five and could meet up.'

Their preparation included symptom management and enhanced communication, training at a local hospice, shadowing, working with a nurse specialist, and sessions around engaging carers and relatives.



They now have more satisfaction in their jobs, without a doubt

Providing optimum care

Maria describes the project as 'a very ground-up approach'. It was important to consider what nursing staff on the wards felt they needed most if they were to provide optimum palliative care. To find out, the resource nurses spoke to colleagues at all levels. 'Then, when the nurses met on a monthly basis, they were bringing back issues that had been identified.'

Last offices, for example, which had caused some concern among ward staff and presented them with challenges. 'The nurses spent a day doing a literature search, looking at the kind of resources out there,' says Maria.

From that they developed an information sheet that was distributed among nursing staff, who were given an opportunity to talk through last offices and the emotional impact involved.

Other initiatives developed by the resource nurses included work on end of life oral care and a ward poster highlighting that end of life care was only one part of wider palliative support. 'It was about recognising change and progression, supporting patients and carers, and then delivering end of life care,' says Maria.

But she didn't focus solely on developing nursing staff. 'We have a staff-grade medic

who monitors the ward Monday to Friday, and we identified a very person-centred learning opportunity for him, and the hospice very kindly delivered a bespoke five-day training package for him.

‘That mimicked the palliative resource-nurse approach in that he shadowed the consultants there. He also shadowed the nurse specialist and spent some time with the pharmacist specialist. It took quite a bit of organising, but it was really beneficial.’

Another part of the project saw Maria asking a palliative care consultant and GP facilitator to come to one of the weekly medical teaching sessions within the hospital, where they talked to psychiatrists, senior and less experienced,

about palliative and end of life care. ‘That link is still there, so if the psychiatrists want more information, the consultant is more than happy to come in and deliver sessions on anything that’s come up.’

‘Anticipatory discussions’ were an important part of the project, too – adopting a proactive approach to talking to relatives about options regarding treatment, resuscitation and transfer to acute care for their loved one if required. Maria says: ‘It was about making sure there was an understanding of the progression of the illness – talking about what the person’s wishes would have been, what was expressed to the family, and obviously whether there is power of attorney and guardianship, and ensuring we were aware of the family’s wishes.’



There was some frustration around wanting to make things better but not being sure how

Anticipating needs

From those discussions, anticipatory care plans evolved detailing how treatment should proceed as an individual neared the end of life.

Junior doctors found these especially useful. Most conversations around transfer of care, for example, happen out of hours. ‘And that’s incredibly stressful for junior doctors because they can’t always find the relevant information when they need it.’

It was also difficult for the family if they received a phone call from someone they didn’t know asking about their wishes and expectations – especially if those wishes and expectations had already been expressed to someone else. ‘It was all quite traumatic,’ Maria says. But the anticipatory care plans made a difficult situation easier.

One simple aim of the DSIL programme is to make things better and Maria says the work she led improved the patient journey for people with advanced dementia nearing the end of their lives. But improvement in dementia care is multi-faceted and to some extent is dependent on how enthusiastic and motivated staff feel about the work they do. Inspiring them and helping them develop is part of good leadership, and Maria was pleased to see the palliative resource nurses grow in confidence as time went on. ‘I think before there was some frustration around wanting to make things better but not being quite sure how to do that,’ she says. ‘This gave them a framework and a structure for how to do things.’ She adds: ‘They now have more satisfaction in their jobs, without a doubt.’

Case Study 5

Catalyst for change

Stephanie Gilfedder admits the challenge was daunting but by working collaboratively with her staff she built an innovative approach to dementia care.

Stephanie recalls that when she first took charge of the ward where she had been appointed senior charge nurse, she felt a little overwhelmed by the scale of the challenge and wondered whether she was out of her depth.

She identified a number of improvements to be made in the area of activity and individualised care. She also realised that there were a lot of incidents of aggression towards staff and patient-to-patient, and that it would be important to reduce the use of medication to manage stress and distress.

But bolstered by her own passion for dementia care and fortuitous timing that saw her begin the DSIL programme soon after she started on the ward, Stephanie initiated the process of transforming the environment into an award-winning example of innovative practice.

Back in 2016 when she took up post, it was a chance conversation with a colleague in occupational therapy that acted as a catalyst for change. 'We spoke about getting patients out of the ward environment, getting them back out into the community, seeing how they managed in the community,' Stephanie recalls. 'That was my plan, but I didn't know how I was going to do it.'

Staff were asked for their ideas. They were enthusiastic and suggestions flowed, though Stephanie knew she faced a challenge in getting everyone to support her vision.

But when the ward moved into new premises, she sensed an opportunity. 'I was thinking, right, new building, new charge nurse, new start for everybody – let's keep this momentum going.'

She considered carefully how care might be delivered differently and describes how ingrained some aspects of clinical practice had become. 'Staff were waking people up in the morning when there was no need. I was thinking, the person's not incontinent, we've got a kitchen here with plenty of food for breakfast – why are we waking them up at 7 o'clock, getting them dressed and into the dining room?' She adds: 'I wouldn't want to go for a shower at 7am on a cold February morning after a stranger's woken me up.'

When she asked why things always had to be done in the same way at the same time, it was a lightbulb moment for many staff. 'Nobody had ever asked the question,' Stephanie says. 'It was as simple as that. It was almost as if I'd given them permission to do it differently.'

There was still hesitation, though, with some feeling uncertain about the need for change. So, Stephanie did something that probably won't be found in any leadership manual – she arranged a ball.

'I pitched this idea,' she says. 'I thought, hospices always do these big fundraisers and balls every year. I'd love to do something like that to raise funds for the ward, for the patients.' Her aim was to generate enough cash to take all the patients, and their families, out for Christmas dinner. The ball would also give a boost to staff morale, she thought.

It proved to be a great success. 'Senior management supported it, and the whole hospital came,' says Stephanie. Various shops and companies were asked by staff to donate raffle prizes and the event raised nearly £3,000.

The Christmas dinner that followed was a huge hit, too. Held in a local restaurant, it demonstrated that when they're in a social setting, people with dementia will often act in ways that may have been thought lost to them since their diagnosis. 'We're treating them

as if they no longer have these social skills but actually, they're still there,' Stephanie says. 'It was a great day, an absolutely brilliant day. And it really perked up the staff.'

That was a turning point. Meanwhile, she had approached a community interest company called Onside Ayrshire, which supports the development of young people and adults through its programmes, activities and values. 'I knew they worked with people with addiction issues, but I asked if they'd ever worked with people with dementia. They said, "No, but we're open to suggestions".

'So, we linked up with them and started getting the patients out of the ward, taking them to golf ranges, bowling, music and dance afternoons.'

The relationship with Onside Ayrshire grew and the company linked the ward with a couple of local schools, primary and secondary. The secondary school pupils had done a sponsored 'Couch to 5k' run and donated the money raised to the ward. 'So we invited them in,' says Stephanie. 'And they were all a bit apprehensive

because they were thinking, "Oh, it's people with dementia, it's going to be an institution". But when they came, they said, "It doesn't even feel like a ward in here".

When Stephanie saw one of the primary schoolchildren playing chess with a patient on the ward, she describes how she turned to a colleague and said, 'That man came to us from a nursing home because the staff couldn't manage him – and now he's playing chess!'

'It's about us going into their world and seeing what's caused the distress,' Stephanie explains. 'Not us driving them into our world, the ward environment, and expecting them to adjust. It's about us upskilling ourselves and changing our practice. For me, that's the way it works.'

The ward's partnership with Onside Ayrshire, which became a project called GAME (Getting to know me, Active assessment, Maintaining meaningful skills, Every day), saw Stephanie and her team win the Best Innovation in Continuing Care category in the 2017 Scotland's Dementia Awards. Other awards followed but the GAME project is no more. It simply became everyday practice, says Stephanie.

She has moved on now to a new role but believes that key to her success in making the ward truly innovative and successful was maintaining 'courage in my convictions'.

'You have to be a strong leader and you have to support staff. If you're not there constantly doing that, they can fall back into their old ways. But equally you have to be appreciative of the hard work they do.'

She admits she was nervous about becoming a ward leader but the DSIL programme strengthened her belief in her own leadership qualities. 'You have to come into this kind of role with a passion for dementia and for leadership. I think I always had that but the DSIL programme really helped me to look at myself and develop myself,' Stephanie says.





The view **from NES**

Susanne Forrest, from NES, believes the graduates from the DSIL programme embody the principles the programme was designed to promote – improving the lives of people with dementia, their families and carers through adopting evidence-based improvement approaches.

‘The programme has shown the value of bringing people from various disciplines and sectors together to share learning and experiences and to grow from that,’ she says. ‘What we’re seeing from the graduates is tangible evidence of positive improvements in the lives of people with dementia, their families and carers. This report highlights some examples, but there are many more we could have cited.’

All of the NES team are particularly impressed by how enthusiastically the cohort participants have responded to the opportunities the programme offers. Working in areas of dementia care, many of the participants have had relatively few professional development opportunities in the past, so taking part in an 18-month education programme might have seemed daunting to some. But from day one of cohort 1, there has been no hesitancy from the participants – they see the programme as an opportunity to flourish and grow, and they have taken it.

Ambi Wildman, a member of the team at NES, has been equally impressed by how the participants have responded to the challenges of the programme. The impact of the graduates has a special significance for Ambi, as she worked in the field of dementia care for many years.

‘It’s a really important area for me,’ she says. ‘I’ve worked with people with dementia and their carers for a long time and know the challenges and joys it can bring. But for so long, it was not at the forefront of priorities when it came to educating professionals. Things are changing now, especially through the Promoting Excellence framework and Scotland’s dementia strategies, and the DSIL programme is taking it up another notch.’

NES team member Theresa Douglas adds to this, saying: ‘I’ve been inspired by the participants in many ways – their openness



The team behind the DSIL programme



Care of older people, especially those with dementia, was pretty far down the list of preferred specialties for nurses when I was practising, so it is fantastic to see these special people choosing to practise in that area. And what an impact they're having

to learning and doing things differently, their ambition for their service, but mostly for their compassion for and dedication to people with dementia.'

The NES team recognise that approaches to meeting the needs of people with dementia, their families and carers continue to evolve, and the programme needs to evolve with them.

'That's why it's so positive to find that graduates are very keen to come back to speak to new cohorts, to share their experiences not only of the programme, which has enabled us to make important changes, but also of how they have moved forward since graduating,' team member Patricia Howie says. 'It's truly inspiring, and it has been a privilege to work with such dedicated and enthusiastic professionals and to watch them grow as confident and inspirational leaders.'

The team is now looking forward to the publication of Scotland's fourth dementia strategy, which will continue to drive

improvements in education and development across the health and social care sector, and to ongoing initiatives to promote the transformation of specialist dementia care.

Learning about the DSILs and the work they have been doing also had a profound effect on the authors of this report – Alex Mathieson and Daniel Allen.

Alex and Daniel are former nurses (Alex specialising in care of older people and Daniel in mental health) who have been working in health journalism for almost three decades, during which time they have interviewed and written about many health-care professionals. But the DSIL experience was, for them, quite unlike any other.

'The immediate impression was that the DSILs are incredibly capable, confident and committed people,' Alex says. 'Care of older people, especially those with dementia, was pretty far down the list of preferred specialties for nurses when I was



practising, so it is fantastic to see these special people choosing to practise in that area. And what an impact they're having.'

Daniel adds: 'What stood out for me when hearing the DSILs describe their work was their inexhaustible desire to bring about change. The DSIL programme seems to have instilled in them, or brought to the fore, their absolute determination to make things

better. And they're clearly fuelled by a deep and genuine passion for dementia care – a quality that helps bring colleagues on board and which has the capacity to make significant, sustainable and quantifiable improvements to people's lives. It was truly a privilege to interview them.'

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Closing thoughts

'It has been a pleasure being involved with the DSIL programme. I can see the benefits of all health and social care professionals working together to take forward a truly multi-disciplinary approach when working with people living with dementia – this is at the

core of this training programme. It has also been beneficial for me as a clinical psychologist, as it has allowed me to network with a wider group, foster good working relationships with all health and social care professionals and share good working practice.'

Dr Claire Donaghey, Head of Programme, Psychology of Dementia, NES



‘[The DSIL programme is] professionally organised and a joy to be involved with. I was at a care home in East Lothian recently talking with the manager about a research project we’re undertaking. She reminded me of a question she asked me at one of the DSIL palliative care days back in 2018. Clearly, she found the course extremely useful and is now passing her knowledge on within the care home environment.’

Dr Jo Hockley, University of Edinburgh

‘As a co-facilitator of the DSIL training programme, I’ve had the absolute privilege of working in collaboration with the three cohorts over the last five years. The professionals have clearly demonstrated their leadership, innovation and change management knowledge and skills by implementing significant improvement within specialist dementia care settings across Scotland. Many of our DSILs have achieved local and national awards for the innovation and implementation of new care models and services for people with dementia living in their communities and in specialist dementia care environments. Several have also successfully achieved promotions within their areas.’

Maureen Taggart, Alzheimer Scotland national dementia nurse consultant

The DSILs aspire to make care better for people living with dementia, and we are delighted to accompany them part of the way. Delivering the complex care component has been a mutual learning experience and a great pleasure. Each DSIL group brings considerable knowledge and experience to explore best practice and challenge preconceptions. Using our evidence-informed care empathy approach to learning, we support this in a spirit of mutual respect.

Dr Margaret Brown, Alzheimer Scotland Centre for Policy and Practice, University of the West of Scotland

‘I was very fortunate to be selected to undertake the first DSIL programme in 2014. The whole process provided me with a structure to implement a development plan to implement Commitment 11 of the dementia strategy [extending the work in improving care for people with dementia in acute hospitals to other hospital settings] in our dementia assessment and rehabilitation wards in NHS Dumfries & Galloway. The programme resulted in me nominating both senior charge nurses for the Mental Health Nursing Forum care of older people award, which they duly won. The DSIL programme opens many doors for people and widens their horizons.’

Lorraine Haining, DSIL cohort 1 graduate

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