The ENACT Project

Empowering Nurses to provide ethical leAdership in Care homes supported by a dignity Toolkit

SUMMARY REPORT

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EXECUTIVE SUMMARY

The ENACT project (**E**mpowering **N**urses to provide ethical le**A**dership in **C**are homes supported by a dignity **T**oolkit) focused on supporting the nursing contribution to dignifying care for older people in care homes. Registered nurses in care homes engaged with the research team and members of the action research groups (ARGs) to develop a Dignity Toolkit. The project aimed to develop nurses' knowledge and skills so they are empowered to provide ethical leadership that enacts the dignity of older people and staff.

A number of reports have detailed dignity deficits in the care of older people in both the NHS and care home sector. It is estimated that 4% of the UK population over 65 lives in care homes, with almost 20% of those over 85 in care homes and 78% of these residents experiencing cognitive impairment.

There has been a great deal of philosophical and research attention to dignity in care. Some members of the ENACT research team and advisory group have been involved in some of this work for over a decade, for example, in an early intervention study and the Royal College of Nursing survey of nurses' views of dignity in care. The project design was action research involving two researchers meeting monthly with two groups - one Action Research Group (ARG) and one Relatives and Residents Group (RRG) - in each of four care homes in the south east of England.

There is no consensus regarding the meaning of dignity in care nor is there an agreed framework to operationalise dignity. The ENACT research team shared insights from previous publications, studies and frameworks in initial work with the expert Advisory group. Insights from materials produced by Skills for Care and by the Royal College of Nursing were integrated. This initiated the development of the first draft toolkit with the expert Advisory group. The expertise of members of the Advisory Group also led to the development of dignity-related activities that were incorporated into the toolkit. Discussion at the monthly meetings with the ARGs, the RRGs, with the expert Advisory Group and the research team enabled the development of the Dignity Toolkit. A generic toolkit, [available online at http://iceobservatorysurrey.org/index.html], bespoke paper versions for each of the four care homes, pocket guides and posters were produced.

Three **overall findings** are: the positive impact of making time and space in care homes for discussion about dignity-related issues for staff, residents and relatives; the project process is as important as project outputs; and the potential of bottom-up collaborative approaches to promote dignity in care requires further research.

This report is in four sections:

Section 1 – Background to the project, aims, objectives, outcomes & methodology

Section 2 – The development & structure of the Dignity Toolkit

Section 3 – Findings from initial and evaluation

Section 4 – Discussion, conclusion & recommendations

SECTION 1 – Background to the project & methodology

1.1 Background to project

The ENACT project (Empowering Nurses to provide ethical leadership in Care homes supported by a dignity Toolkit) proposal was developed in response to a call from the Burdett Trust for Nursing on the theme of 'Delivering Dignity through Empowered Leadership'. The ENACT project was one of a number of projects funded on this theme and focused on supporting the nursing contribution to dignifying care for older people in care homes.

Registered nurses in care homes engaged with the research team and members of the action research groups (ARGs) to develop a Dignity Toolkit over a one year period (November 2013 to December 2014). The project aimed to develop nurses' knowledge and skills so they are empowered to provide ethical leadership that enacts the dignity of older people and staff in care homes.

In 2010, the *Delivering Dignity* report (1) estimated that 10.3 million people in the UK (17% per cent of the population) were aged 65 and over, with 1.4 million people aged 85 and over, In England, more than 400,000 people aged over 65 are living in over 18,000 care homes. The report emphasised the role of care homes in taking responsibility for maintaining dignity and in safeguarding vulnerable older adults. A recent Adult Social Care survey found that up to 50% of older people in care homes feared abuse and many felt that their dignity was undermined (2). A report from The Northern Ireland Human Rights Commission (3) detailed specific areas that render older people in care homes vulnerable to indignity, for example, in relation to personal care, eating and drinking, medication and restraint.

Although dignity remains a contested concept in bioethics (4, 5), research and scholarship in nursing and care ethics has provided a good understanding of the meaning and importance of dignity in the care of older people. Research found that what was important to older people was the preservation of self-identity and confirmation of their value as persons, regardless of their capability (6, 7). Other research highlights the importance of working in care homes with a good organisational culture, one that supports nurses and nursing values (8).

There are many different definitions and philosophical frameworks relating to dignity (see, for example, 9, 10). The ENACT team agreed that a helpful definition is included in the Royal College of Nursing (RCN) report (11 p.8). This states that:

> 'Dignity is concerned with how people feel, think and behave in relation to the worth or value of themselves and others. To treat someone with dignity is to treat them as being of worth, in a way that is respectful of them as valued individuals.
>
> In care situations dignity may be promoted or diminished by: the physical environment; organisational culture; the attitudes and behaviour of nurses and others; and in the way care activities are carried out. When dignity is present people feel in control, valued, confident, comfortable and able to make decisions for themselves. When dignity is absent people feel devalued, and lacking in control and comfort. They may lack confidence and be unable to

make decisions for themselves. They may feel humiliated, embarrassed or ashamed.

Dignity applies equally to those who have capacity and to those who lack it. Everyone has equal worth as human beings and must be treated as if they are able to feel, think and behave in relation to their own worth or value.

Nurses should, therefore, treat all people in all settings and of any health status with dignity, and dignified care should continue after death.'

A framework from Skills for Care (12) was also utilised by the ENACT research team in developing the Dignity Toolkit. The framework included 7 '**common core principles'** relating to dignity. These are:

Principle 1 – Value the uniqueness of every individual.

Principle 2 – Uphold the responsibility to shape care and support service around each individual.

Principle 3 – Value communicating with individuals in ways that are meaningful to them.

Principle 4 – Recognise and respect how an individual's dignity may be affected when supported with their personal care.

Principle 5 – Recognise that an individual's surroundings and environments are important to their sense of dignity.

Principle 6 – Value workplace cultures that actively promote the dignity of everybody.

Principle 7 - Recognise the need to challenge care that may reduce the dignity of the individual.

These principles were included in the initial version of the Dignity Toolkit and reduced in number as the action research process progressed (See Section 2 of this report).

The NMC code of conduct requires of nurses that they:

'make the care of people [their] first concern, treating them as individuals and respecting their dignity' (13).

While some nurses have formal leadership responsibilities, all members of the profession are expected to take responsibility for influencing dignity in care and as such might be understood to be 'ethical leaders'. Whether or not nurses have formal leadership responsibilities, ethical leadership can be understood to have a number of facets and incorporate different leadership styles (14). Gallagher and Tschudin suggest that ethical leadership aspires to promote good ends at the same time as paying attention to how those ends are reached (15). Ethical leadership is also

concerned with influencing others to behave ethically, for example, through role modelling (16).

The concepts of leadership and empowerment are closely related. Influence is itself a form of power and leadership requires both formal and informal power (17). Further, Koukkanen et al include in their model of the qualities of an empowered nurse those of 'moral principles' and 'personal integrity'. An empowered nurse is someone who acts ethically, in a way that is honest and just, and treats others with respect (18). Finally, just as nurse empowerment is understood in the context of the individual, the organisation and socio-cultural conditions, so too does leadership extend into each of these domains, operating at the micro-, meso- and macro-levels (11).

Nurses play a key role in providing ethical leadership that promotes and sustains dignity in care homes. However, they require support and resources to do this well. In other words, to be empowered to provide ethical leadership. However, there is little research regarding 'what works' in developing sustainable and dignifying care. While there have been a number of initiatives to 'embed' dignity, anecdotally, there is a tendency for these initiatives not to be well integrated into care home practice. Therefore, the project aimed to build on the experience of RNs to provide ethical leadership using an action research process (19) to develop a toolkit that is appropriate to the context of individual homes, and over which the staff take ownership.

1.2 ENACT Project aims, objectives & outcomes

The overall aim of the project was:

- To empower registered nurses to provide ethical leadership that enacts the dignity of older people and staff, through action research.

The objectives were:

- To develop, implement and evaluate a nurse-led Dignity Toolkit in care homes in collaboration with staff, residents, relatives and other experts
- To develop registered nurses' knowledge, skills and confidence so that they are empowered to provide ethical leadership
- To develop registered nurses' research capacity

The anticipated outcomes of the project were:

- The development of a Dignity Toolkit that supports nurses in providing leadership that sustains dignity in care homes, produced through the process of action research integrating the experience of key stakeholders and with the potential to be rolled out across health and social residential care.
- The implementation of the Toolkit with delivery by nurses – the model will be 'training the trainers' with team members working with registered nurses to develop their confidence and competence as dignity in care facilitators drawing on resources from the Dignity Toolkit.
- An evaluation of the impact of the project on older people's and staff dignity in residential care homes

1.3 Methodology

The methodology is action research. Action research is research 'with' participants rather than 'on' them. The 'experts by experience' in this project are older people, relatives and care home staff. The action research process is cyclical and consists of planning, action, monitoring and reflection, with on-going evaluation.

Action research is:

> 'A participatory, democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes … it seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities' (19)

According to Williamson

> 'Simply put, action research is a process by which change is achieved and new knowledge about a situation is generated' (19 p.7)

Action research is participatory, with the members of the Action Research Groups positioned as co-researchers rather than simply participants. In this project, the aim was to engage the RNs in particular as co-researchers, initiating changes in their practice and then evaluating the impact of those changes. At the same time, members of the research team were also fully engaged as action researchers, reflecting on their own practices as researchers and teachers in social care ethics.

The action research groups (ARGs) for staff in each care home were used to:

(i) Introduce and discuss the project (Session 1).
(ii) Develop the toolkit – focusing on one topic in each group meeting (Sessions 2 to 5).
(iii) Enable staff to consider how the Toolkit may be best utilised in care homes.
(iv) Evaluate the toolkit and the action research process and agree next steps (Session 6).

Nurses in the care homes were supported to implement the toolkit. As well as the action research groups, in each care home there was a 'reference group' of residents and relatives – relatives and residents groups (RRGs) - which also met monthly to discuss and provide feedback to inform the project.

In addition, the research team carried out a qualitative evaluation (20) of the impact of the project on a) the knowledge, skills and confidence of nurses involved in the implementation of the Dignity Toolkit and b) the dignity of older people and staff in residential homes. The researchers undertook individual interviews with registered nurses participating in the ARGs at the beginning and end of the project. The interviews focused on the nurses' views on dignity, their understanding of their roles in promoting dignity, and their views on their levels of confidence, knowledge and skills in working with colleagues to promote dignity in care. The meetings of the

ARGs and RRGs were audio recorded, with the researchers making notes during and after the meetings. Qualitative data were analysed thematically.

Participating care homes were identified using existing contacts. Four care homes in the South-East of England took part in the study. Two of the homes are part of a large, national provider of care homes. One is part of a smaller group of care homes. The fourth is an independent home. All homes provide dementia care; three of the four homes also provide for those with physical health and personal care needs only.

In each home, we aimed to meet monthly with a group of staff (the Action Research Group/ARG) and a group of residents and relatives (RRGs). The numbers in each group varied between homes and between meetings, with between 1 and 7 participants. The Action Research Groups included between 1 and 2 RNs and other care-givers. In 3 of the homes, each group met 6 times, with the ARG in 1 home meeting 4 times and the RRG meeting 5 times. The meetings took place over the course of approximately 6 months and lasted for approximately 1 hour each

Participants: Action Research Groups (ARGs)

Home	No. Participants	No. RNs	No. Meetings	Maximum Attendance	Minimum attendance
A	9	2	6	7	1
B	7	1	6	7	2
C	6	2	4	6	3
D	7	2	6	7	3

Participants: Residents' and Relatives' reference Group (RRGs)

Home	No. Participants & Composition	No. Meetings	Maximum Attendance	Minimum attendance
A	3 - 1 resident, 2 relatives	6	3	1
B	5 - 4 residents, 1 relative	6	5	2
C	5 - 3 residents, 2 relative	5	4	1
D	5 - 1 resident, 4 relatives	6	4	1

The ENACT project was reviewed by the University of Surrey Research Ethics Committee and a favourable ethical opinion was obtained. Letters were sent to care home managers, explaining the aims of the project and requesting their involvement. Potential participants were provided with Participant Information Sheets inviting them to participate, and were given time to consider the information and ask questions. Those who were willing to participate were invited to sign a consent form.
All data was anonymised so that individuals and organisations are not recognisable and confidentiality has been maintained. It was explained to participants that their confidentiality and anonymity would be protected, except where there were any disclosures of harm to individuals, in which case the researcher would report this to an appropriate authority. Data were stored securely in accordance with Data Protection law.

SECTION 2 – The development & structure of the Dignity Toolkit

The development of the Dignity Toolkit was iterative with a first draft prepared and expanded with the help of the expert Advisory Group. The sections of the Toolkit were then discussed and amended in the light of discussion with the ARGs and the RRGs. The 7 'common core principles', for example, were reduced to four statements:

1. Support and care for me in ways that value who I am
2. Communicate with me so that I am understood and my needs are met
3. Work together to provide care that is safe and respectful of my feelings and to create an environment where I can feel at home
4. Be prepared to speak up on my behalf and on behalf of others, in order to protect and promote everybody's dignity.

The Toolkit consisted of 4 sections initially and a fifth section was added following in the interviews with the registered nurses (RNs). The structure of the final Toolkit is as follows:

Section 1 - Understanding dignity – this section suggests some ideas to assist RNs to help members of their team to reflect on the meaning of dignity and how it relates to everyday practice in the care home.

Section 2 – Dignity Principles – this suggests how RNs can introduce colleagues to dignity statements and to encourage them to use the pocket guide to reflect on their practice.

Section 3 – Communicating dignity – this includes tips to help the care home team demonstrate dignity in their everyday communication with residents, families and others.

Section 4 – Dignity group conversations – a structured format is suggested to help RNs lead discussions relating to care situations that are ethically challenging.

Section 5 – Ethical leadership & empowerment – this final section gives RNs the opportunity to reflect on what is meant by ethical leadership and to identify the ways they can build on their leadership skills.

The Toolkit also includes a list of further resources and Appendices detailing RCN and Skills for Care approaches to dignity. Based on the feedback from the previous meetings, the research team developed the Toolkit further to present to the groups during the 5th meeting. This 'bespoking' of the Toolkit for each home included adding the responses from the staff and resident and relatives on their understanding of dignity and dignified care, and including their '10 Top Tips' for communication'. Other changes based on feedback included replacing a Workbook with a pocket guide.

Laminated pocket guides, posters and A5 versions of the Toolkit were produced for each home. The Dignity Toolkit was converted to an online version and is available at http://iceobservatorysurrey.org/index.html . This is free to access for all.

SECTION 3 – Findings from initial and evaluation interviews

3.1 Initial interviews with RNs

The initial interviews with the RNs involved in the project explored their understanding of dignity and its practice in their care home, their roles in providing leadership on dignity, and their views on what enabled or inhibited the provision of dignified care. The interview data were analysed thematically (21), and 3 main themes were identified: dignity in care; conditions for dignity in care; and leading dignified care.

Theme 1 'Dignity in care' describes the participants' views of dignity and dignified care. It contains 2 sub-themes, 'Understanding dignity' and 'The practice of dignity'.

'Understanding dignity' includes the ways in which the participants conceptualised dignity. For example, dignity was understood as seeing and valuing the person and as treating others the way you would like to be treated:

> *… to treat somebody with dignity is to ... to treat them as you would like to be treated yourself, with respect as well. To not impose your wishes on them, to remember that they are people [AA1]*

> *[The residents] are not numbers - number 1, number 2 - they are not objects. They are people, they need attention, they need some care [CA1]*

The second sub-theme relating to the 'practice of dignity' focuses on the way in which dignity is delivered in practice. Here, paying and giving attention to residents and their families was seen as important to dignifying care:

> *… it doesn't matter how far you think the dementia's gone if you actually take the time to get to know somebody. Even if they can't verbally communicate with words, they could just communicate with voices, you can see that they understand because they respond to your voice if you take the time and trouble to know them. And you can see in their eyes when you get to know your resident the different responses and the changes to different things, different stimuli, different questions and things like that [AA1]*

> *But the thing is … nobody comes to see her ... But now you know people are paying attention, just one minute holding her hand, 'How are you?' and all that, you know still they are sitting with her and all that – it made major changes in her" [DA2]*

It was stressed that it was often 'the little things' that made the difference

> *But it's all sorts of little things as well, and it's just stopping and you know spending the time of day with somebody. Somebody walks past, and you know as you're walking past somebody puts their hand up and you carry on walking – it denies them and it takes a little bit of dignity away from them, makes them feel that they're not important. I think dignity - it's just a huge word isn't it, it covers so many different aspects [BA1]*

T**heme** 2 'Conditions for dignity in care' describes the ways in which interview participants referred to the wider requirements for providing dignified care in residential homes for older people. This theme also includes some of the obstacles to providing dignified care. For example, dignified care was seen to require both carers who value the work of care, and a society that values the work of carers, including adequate economic rewards. The view was also expressed that in order to provide dignified care, you need to be 'the right kind of person':

> *So I think we do need to do more to value our carers. I think if you valued our carers more then it would have a knock-on effect … and if we can't pay them more, then we need to find other ways [BA1]*

> *I'm working here because I like this job, I like work with elderly people, I like work with people with mental problems, because it was my previous job in my country. But it's not an easy thing to do – deal with this kind of people. And some carers coming here only because they need a job, they need money [CA1]*

Theme 3 'Leading dignified care' describes participants' views on and experiences of leading dignified care. It includes the sub-themes: the leadership role and the practice of leadership. In talking about their leadership role, the RNs acknowledged the responsibility that goes with having a leadership role within their care homes:

> *… every single complaint comes here, comes to me [CA1]*

> *[When] I'm in charge of the shift, and if someone phones up sick I need to find staff. I mean there is pressure to be in charge of a shift. Cos if something happens from not having you know enough supplies let's say like for milk - until you know really massive important things – they come to me [DA1]*

They also described the extent to which they had confidence in their own and others' leadership, with confidence coming from experience and lack of confidence coming from perceived lack of experience

> *I think [I'm] very confident. I'm older than obviously a lot, I tend to be the old school nursing – we were talking about that this morning – how when I trained you trained on the wards … Now they're all in university and just come out for bits and things, and we trained on the ward. And I think it's very different because you are people-orientated from the word go [AA1]*

Trust, and sometimes lack of trust in their staff was also referred to:

> *I have a fairly small team, but we're all working towards a common goal … We're lucky to have found them … I rely on them very much [BA1]*

> *I need to do the same [care] procedures with the residents … but I know what I have to do … But I have to check if the others are doing the same [CA1]*

Finally, having a leadership role was understood in the context of being part of the team, so that while the responsibility of the leadership role was seen as sometimes separating them from other team members, the importance of being prepared to work alongside care staff was also emphasised.

3.2 Evaluation interviews with RNs

In the second semi-structured interview, RNs were asked about their experiences of developing and using a Dignity Toolkit, their understanding and experiences of ethical leadership and empowerment, and finally about their experience of taking part in research and thoughts on future research in this area. Attention was paid to any changes that had taken place and to the obstacles that the RNs had encountered.

The data were analysed deductively and inductively and grouped into 2 themes: 'Developing dignity in the care of older people'; and 'ethical leadership and empowerment'. Participants were asked about their experiences of developing a Dignity Toolkit through the Action Research process. One of the positive experiences reported was the opportunity to share experiences. This had led to a broadening and deepening of their understanding of dignity:

> *…it's all been beneficial because it's good to hear, specially within the group discussions ,other people's thoughts and ideas which they maybe wouldn't express on the unit or in unit meeting [AB1]*

At the same time, this opportunity had been experienced as valuable in itself, with RNs appreciating the chance for themselves and their colleagues to be heard and to have their views taken seriously:

> *… for me the positive thing was we could say what we want to say and [the researchers] ... didn't tell us [their] point of view ... we could be really honest without judgement [AB2]*

The participants described the impact of their participation on dignity in their care home, including changes that they had already made to their practice

> *I've started to allocate more time with the residents. For example, if I'm attending someone I'm not you know just thinking, 'Oh at 8 o'clock, I need to start medication, blah blah blah, cos I've got so much to do'. I just allocated you know more time - 5, 10 minutes more - just have a conversation, just trying to say to that resident, ask the resident what he would like to do today, or what he would like to eat, what he fancies, what I'm fancying today. And just sharing opinions about daily activities or just having small conversations while giving care. It's making, this way of approaching the residents, I think it's going to make things easier for the resident, for the way he feels you know […] [DB1]*

In some homes, the use of the Toolkit had already had some impact

> *I think this one was quite nice – Activity 2 – to assist colleagues in understanding and applying dignity – 'Support and care for me in ways that value who I am'. And we got people to think about how would you feel, you*

know if you're coming into a care home what would be the most important things for you but people might not necessarily know, it might not be in your medical file, it might not be, you know cos quite often we get a lot of information from nearest and dearest [but] it might not be something that they know. And I got everybody to tell me something that was desperately desperately important to them but perhaps other people might not know. And what would happen, how would they feel if that didn't happen?" [BB1]

In most of the homes there appeared to have been little use of the Toolkit outside of the ARG meetings. However participants described a number of ways in which they intended or would like to use the Toolkit in future.

Regarding the second theme of 'ethical leadership and empowerment', participants were asked about their understanding of ethical leadership, and their own role as an ethical leader. For some participants, ethical leadership was understood in terms of ethical decision making

And if I think of ethical as well, it's about managing things like the mental capacity of people to make sure that you're making those decisions correctly and supporting people those decisions and that you're doing things for the right reasons, not for any other [BB1]

Overall, the participants felt that they were empowered, by virtue of their position and responsibilities, and the support and expectations of their managers. One participant reflected on the relationship between care for the individual resident and the wider context in which that care is provided:

No it was really nice actually, really really nice, this project. And hopefully I think we will see and act with this, because it's so important. I'm terrified sometimes when I see - I don't want to see more problems [on] TV and all of that about nursing homes … because I've got this kind of passion for elderly people, and I just want all of them to be happy ... But the majority of the society don't understand how undignified it is just to, you know, put someone in a care home and just stay there – it's so horrible. And if I could change, even if it was a little bit, change [someone's] life and make them feel useful because they are useful, it will make all the difference for me at least and ... even if it's just for one person, if I can change the way people, society look to persons in nursing homes, I would be really really happy. And I will use all the resources I've got and this [Toolkit], everything what I can use to change that, I will do it for sure. And of course all the universities … are really [in talking about] these things … and it's 'Oh of course we treat everybody with dignity' and it's not truth. It's not truth. So it's amazing what the universities can do … but please let's act. Let's do something [AB2]

Section 4 – Conclusion & recommendations

The overall aim of the ENACT project was:

- To empower registered nurses to provide ethical leadership that enacts the dignity of older people and staff, through action research.

The objectives were:

- To develop, implement and evaluate a nurse-led Dignity Toolkit in care homes in collaboration with staff, residents, relatives and other experts
- To develop registered nurses' knowledge, skills and confidence so that they are empowered to provide ethical leadership
- To develop registered nurses' research capacity

The first outcome of the project was achieved in that a Dignity Toolkit and other educational materials were developed through the action research process and with the input of an expert advisory group. The Toolkit has been made available the participating care homes in hard copy A5 versions and with accompanying laminated pocket guides and posters. With input from University of Surrey Department of Technology Enhanced Learning Education, an online version was created – see http://iceobservatorysurrey.org/index.html

It was intended that a 'train the trainers' model would be implemented with team members working with registered nurses to develop their confidence and competence as dignity in care facilitators drawing on resources from the Dignity Toolkit. The project evaluation suggested that participants gained in confidence regarding their understanding of dignity in care homes and that they found elements of the Toolkit helpful.

There were three striking overall findings. The **first** is the positive impact of making time and space in care homes for discussion about dignity-related issues for staff. This was valued highly by staff, residents and relatives. Related to this is a **second** finding, and this is that the project process is as important as project outputs. Being listened to and having one's views considered important was highly valued by participants. The project overall suggests the potential of bottom-up collaborative approaches to promote dignity in care. **Third,** regarding future recommendations, we suggest the following areas for further research, educational and practice-related activity:

- Develop longer term partnerships between care homes and researchers/academics with expertise in ethics/professionalism to research strategies that sustain dignity in care;
- Direct care home providers to the online Dignity Toolkit (http://iceobservatorysurrey.org/index.html) and encourage engagement, utilisation and suggestions for further development; and
- Highlight the value of making time and space in care homes for staff, residents and relatives to reflect on the complexity and value of everyday care practices.

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