



GETTING IT RIGHT!

Guidance on a Human Rights-Based
Approach to Dementia

GETTING IT RIGHT!

The DEMENTIA RIGHT – DEVELOPING A RIGHTS-BASED APPROACH TO DEMENTIA aims to improve the quality of life, social inclusion and dignity of people living with dementia, their carers and families, by developing effective guidelines for the implementation of a rights-based approach to dementia, including healthcare settings, to better meet the needs, will and preferences of people living with dementia.

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Kevin Quaid

Kevin became the first person in the world to write a book about Lewy Body dementia from the person's point of view called 'Lewy Body Dementia Survival and ME'; a book about what it's like to be given a diagnosis of dementia. His second book called 'I am Kevin not LEWY' explains what a person can achieve after receiving a diagnosis of dementia. Kevin is currently the chair of the Irish dementia working group for the Alzheimer's Society of Ireland, vice chair of the European working group of people with dementia for Alzheimer Europe and co-founder of Lewy Body Ireland. The Dementia Right partners are deeply grateful to Kevin for his involvement and advice with this project. It was our privilege to work with him and to hear his voice.

FOREWORD

FROM KEVIN QUAID

I am Kevin Quaid and I was diagnosed at the age of 53 with Parkinson's disease and a few months later, Lewy Body Dementia. The day I was given my diagnosis the only word to resonate with me was 'Dementia' and I was positive that I had been given the incorrect diagnosis, little did I know then, that dementia is just an umbrella term for approximately 400 different types of dementia, and like no two dementias are the same, no two people are the same.

I began on my journey of advocacy work for people who not only are living with dementia but people who are affected by dementia, like my wife and family.

I have it, they live with it.

I always took human rights for granted but since I was diagnosed I see on a daily basis that the human rights of people living with dementia are just not being met and it's up to people like me to ensure that our voices are heard.

I am calling right now as you read this, if you are a policy maker, involved in an organisation, a member of the public or private company, to look at how you treat people who are affected by dementia and see what changes you can make and if you can, I urge you to make those changes.

Care givers and family members need to be heard and listened to as well and they need to stand up for their loved ones and know what their rights are; if we all speak in one voice and speak together for the human rights of the person living with dementia, then that voice becomes a choir and a loud one at that.

Small changes can lead to big changes and big changes, they can and do lead to better lives for everyone. Don't ever forget that as long as a person has a voice it's a basic human right for that voice to be heard, and everyone deserves to have their basic human rights heard and met.

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GETTING IT RIGHT!

Human rights and dementia or the
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HUMAN RIGHTS

Human rights are fundamental rights and freedoms that are considered essential for every individual to live with dignity. These rights are enshrined in international legislation, such as the Universal Declaration of Human Rights, and focus on equality, dignity, respect, freedom and justice and are inherent to all human beings, regardless of any other condition.

They cover a wide range of areas, including civil and political rights, as well as economic, social, and cultural rights, and aim to protect the basic needs and interests of all people. Civil and political rights refer to a person's ability to participate in the political and civil aspects of their community without discrimination or oppression. This category encompasses rights such as the right to vote, freedom of speech, privacy, and freedom from abuse. On the other hand, economic, social, and cultural rights relate to a person's ability to flourish and grow, as well as to participate in social and cultural activities. This category includes the right to health, education, and work.



HUMAN RIGHTS ARE UNIVERSAL

They apply to all people, everywhere in the world, and without any time limit. Furthermore, every person has the right to enjoy their human rights without discrimination on the basis of race or ethnicity, skin color, gender identity or sexual orientation, disability, language, religion, political beliefs, social status, national origin, birth or any other status.

This means that all human beings are entitled to their Human Rights, and they apply equally to all people, regardless of their background or circumstances.

HUMAN RIGHTS ARE INDIVISIBLE

They are intrinsically linked and cannot be seen in isolation from one another. Access to one right is dependent on access to all other rights. This means that no single right is more important than another and that the violation of one right often leads to the violation of others.

It is not possible to assume that anyone, regardless of their circumstances, can live a life free from the deprivation of a human right, as this would leave them in a vulnerable position with potential violations of all their other rights.

HUMAN RIGHTS ARE INALIENABLE

They are linked to human existence itself, and are intrinsic and inherent in all human beings. These rights cannot be taken away by any person or institution, and they do not have to be earned or inherited.

However, in special circumstances provided by law, some rights may be restricted. These restrictions should be limited to what is strictly necessary to protect other rights.

For example: In a national emergency, a government may impose restrictions such as a curfew.





DEMENTIA

Dementia is a general clinical term used to describe a group of progressive brain disorders, which have different causes but share many similar symptoms and most of which, at present, have no cure. Symptoms include loss of cognitive functioning; thinking, remembering, and reasoning to such an extent that it interferes with a person's daily life and activities.

Contrary to many people's beliefs, dementia is not a normal part of ageing, although the greatest risk factor is increasing age. There is growing scientific evidence that a healthy diet, exercising, mental stimulation and socialisation, not only contribute to a healthy body and heart, but also keep the brain healthy, which reduces the risk of developing dementia.

Several diseases can cause dementia, the most common form and probably the best known is Alzheimer's Disease. Alzheimer's is a progressive disease, more common in people over the age of 65 (but it is important to recognise, there are many incidences of young onset dementia, those people under 65), where individual brain cells become damaged by plaques and tangles which disrupt neural pathways and the brain atrophies or shrinks

in size. Each person is affected differently depending on which brain cells are damaged. Symptoms often start slowly and progressively worsen. Remembering recent events is often the most common early symptom, but as the disease progresses people experience, language problems and disorientation, mood swings, depression, and social withdrawal.

Another common form is Vascular Disease, which is caused by a stroke or a series of mini-strokes. The symptoms can occur abruptly and while Alzheimer's disease progresses at a steady pace, Vascular dementia progresses in stages or steps following each tiny stroke, so a person's decline is more noticeable following each vascular episode.

Other forms of dementia include Dementia with Lewy Bodies and Frontotemporal Dementia. There are many other rarer forms of dementia e.g. Korsakoff's Syndrome, Creutzfeldt Jacob Disease and Progressive Supranuclear Palsy. Many people can have a mixture of these disorders.

LIVING WITH DEMENTIA CAN BE CHALLENGING

Dementia often starts with cognitive and behavioural changes; memory loss, usually short term initially where a person may not remember a recent event. Dementia can also affect someone's intellect leading to the inability to make complex decisions, perform complex tasks or learn new things.

A person's ability to interact socially is often affected, where they find it difficult to follow a conversation, or express themselves and can speak inappropriately, this all results in the person withdrawing into themselves and becoming socially isolated. At a more advanced stage memory loss becomes more profound; the person may not recognise their own home, or know how to use a knife and fork and may believe they are living in their 'past life'.

Dementia can also affect the senses; a person may lose the ability to see in 3D, which affects their spatial awareness. The perception of colour can be diminished, a person with dementia may not see colour as brightly as before, and without enough contrast in their environment, may have difficulty understanding where one thing ends and another begins. A person's hearing may be affected where sounds are perceived much louder and often can become overwhelming and disrupt a person's ability to pay attention to anything else.



THE NEED FOR A HUMAN RIGHTS-BASED APPROACH TO DEMENTIA

Dementia impacts not just the person but the whole family and the person caring for the person living with dementia, and can give rise to high levels of stress. It affects the whole person, not just the brain, in all aspects of daily living. People living with dementia often feel isolated from other people as a result of their symptoms.

Dementia also affects a person's capacity to make some or all decisions about their everyday lives, including their money, health and welfare. It gradually affects their ability to communicate and act in their own interests and therefore compromises their ability to protect their rights.

Too often, people living with dementia experience discrimination and treatment that contravenes their Human Rights. People living with dementia are often at greater risk of physical, psychological and institutional abuse, neglect, or financial exploitation.

People living with dementia and their carers have the same Human Rights as every other citizen. However, it is widely recognised that, in addition to the impact of the illness, they face cultural, social and economic barriers to fulfilling these rights. It must be recognised that those people living with young onset dementia, often experience an even greater impact on their Human Rights, due to difficulty accessing appropriate services. A lack of knowledge or understanding about dementia may lead to poor care and support, affecting the rights of people living with dementia and their carers.



There are three key reasons why people living with dementia can face discrimination and treatment that contravenes their Human Rights:

- Ageism
- The stigma and discrimination associated with the condition
- Their lack of capacity to challenge and report incidents that occur

Stigma and ageism are major barriers which prevent older people from realising their Human Rights. Older people are often seen as recipients of care rather than rights holders. Many older people have internalised ageism and see themselves as burdens rather than people with rights and entitlements. Stigma is multiplied in the case of older people with a disability such as dementia.

LIVING WITH DEMENTIA CAN BE BETTER

The Lisbon Treaty and the convergence between intergovernmental Human Rights frameworks of the Council of Europe and the United Nations, focusses on equality and Human Rights as a core element of the European Union's goals. Antidiscrimination and Human Rights laws protect people from being treated less favourably because of their age, disability, gender, race, religion or belief and sexual orientation or transgender.

This requires all Europeans to fully consider the impact that changes in policy, such as the closure of services, have on people with "protected characteristics" such as disabilities. Carers of people living with dementia are the duty bearers of their Human Rights and should by definition ensure that they are not disadvantaged. Consideration should also be made to Advanced Care Planning (ACP) for people living with dementia in order to achieve their right to choose their care into the future. This is often difficult as there are many barriers to participating in ACP, these must be overcome, but this will take time. The European Association for Palliative Care (EAPC) has issued white papers on palliative care in dementia including advance care planning, to provide guidance for clinical practice, and to aid reforming policy.

Despite persistent progress, people living with dementia and their carers continue to experience discrimination and treatment that contravenes their human rights. In many cases, discrimination is embedded in the design and culture of the delivery of care and support services.

As a result, people living with dementia are less likely to receive a diagnosis or post-diagnosis support, than people with other long-term conditions. There must be significant work to dispel the stigma of dementia to challenge this inequality and to recognise a person's will and preference at all stages of their lives. People living with dementia have the right to be cared for by people who have been educated in specialist dementia skills.

Changing attitudes and practices to ensure that the rights of people living with dementia are fully recognised continues to be a major challenge for European and International organisations responsible for the provision of health and social care.

We cannot remove all risk, but we need to keep striving to balance risk or make positive risk decisions within person-centred care, respecting human rights and maintaining overall well-being and quality of life. People living with dementia and carers should be treated with dignity and receive care and support that is based on individual needs, rather than assumptions about the condition. In the community, the contribution of people living with dementia should be valued. Professionals must strive to make the wishes and preferences of the person living with dementia influence delivery of care.



SEE IT, KNOW IT, PROMOTE IT

What constitutes a person-centred, rights-based approach to people living with dementia and how can we bring it to life?

THE HUMAN RIGHTS-BASED APPROACH IN THE PRACTICE OF CARE

You now understand what Human Rights are and a little more about dementia and how people living with dementia are at a greater risk of having their Human Rights violated. You also now understand that Human Rights for people living with dementia are no different to Human Rights for people who don't have dementia; that we are all the same.

In this chapter, we intend not only to demonstrate how a Human Rights Based Approach (HRBA) is put into practice, but also to reinforce the importance of looking at how carers work as a whole, and the fundamental role that each element has in how carers work with and care for people.

We invite you to learn and think about a new way of looking at the fundamental rights of people living with dementia.



SEE THEIR RIGHTS

See the person as an individual, not dementia. We all have our own likes and dislikes, our own life story, which tells us more about who we are than a diagnosis does. A Human Rights-based approach is an approach that gets to know people, their needs, will and preferences and enables for advance planning of care.

KNOW THEIR RIGHTS

Understanding dementia isn't only about diagnosis and being able to identify symptoms. But reducing stigma and knowing how to respect and respond to the needs, will and preferences of people living with dementia.

PROMOTE THEIR RIGHTS

A Human Rights-based approach is an approach that enables, engages, commits and makes everyone accountable for protecting and promoting the rights of people living with dementia. That cultivates a critical and reflective attitude towards procedures, which it uses as a tool for positive change and continuous improvement of practices.

PERSON-CENTRED APPROACH TO PEOPLE LIVING WITH DEMENTIA

It is not possible to think about providing care for people living with dementia, without talking about the Person-Centered Approach, developed by Tom Kitwood in the 1990s; which places the person at the center of their care, valuing them regardless of their age or cognitive abilities.

For this to be possible, it is essential to know their identity, their life story, habits, interests and opinions, but also their abilities, desires and ambitions. The focus will always be on the person and their “strengths”, and not on their existing losses or difficulties.

One of the key concepts addressed by Kitwood regarding the way we relate to people living with dementia is ‘Personhood’, which according to him is a position or status that is granted to a human being, by others, in a context of relationship and implies recognition, respect and trust.

To respect and maintain this status throughout life, in 2007, Dawn Brooker, a colleague of Tom Kitwood, described 4 essential elements that define a powerful culture of person-centred care.



V

VALUE

Value people living with dementia and the people who care for them; promote their rights and citizenship regardless of age or cognitive impairment.

I

INDIVIDUALITY

Treat people **individually**; appreciate that all people living with dementia have a unique history, personality, physical and mental health, social and economic resources and that these will influence their response to the neurological disorder.

P

PERSPECTIVE OF THE PERSON

Look at the world through the **perspective of the person** living with dementia, recognizing that each person's experience has its psychological validity, that the person with dementia acts according to their perspective and that empathizing with this perspective has great therapeutic potential.

S

SOCIAL ENVIRONMENT

Recognize that all human life, including that of people living with dementia, is based on relationships and that people living with dementia need a rich and diverse **social environment** that can both compensate for their deficits and provide opportunities for personal growth.

As well as being guidelines, these principles are also useful in allowing carers to continuously assess and analyze the way they act in relation to people living with dementia. The person-centered approach is not a single action, but the way each carer is and how they relate to the person.

Brooker shares several questions that can help to reflect and incorporate these principles in daily practice, whether that is administering medication, attending to personal care, or facilitating a group activity:

- Do my actions show that I respect, value and honour this person?
- Am I treating this person as a unique and individual being?
- Am I really trying to see my actions from the perspective of the person I'm trying to help?
- How will my actions be interpreted by them?
- Do my actions help this person feel socially confident and involved? That he/she is not alone?

SEE IT

See the person as an individual, not the dementia. We all have our own likes and dislikes, our own life story, which tells us more about who we are than a diagnosis does.

SEE IT

PSYCHOLOGICAL NEEDS OF PEOPLE LIVING WITH DEMENTIA

This approach is considered a humanistic, morally ethical and a dignity-promoting philosophy, it reminds us of the importance of considering and meeting the psychological needs of people living with dementia.

Unlike other authors, Kitwood did not consider these needs in a hierarchical way, but - like human rights themselves - as needs that overlap, are interconnected and that culminate in the central need to feel love. It is therefore important to look more closely at each of these needs, which are not exclusive to people living with dementia.

Kitwood reinforces that these needs are present in all human beings, but that they are intensified, and sometimes unanswered, in people with some types of dementia, as they are generally more vulnerable or less able to perform certain actions that allow them to satisfy these same needs.

COMFORT

Importance of the person living with dementia feeling tenderness, closeness, absence of pain or anxiety. Feeling of security that arises from being close to someone / others.

ATTACHMENT

As social beings, we have a need to feel connected to others, particularly in times of heightened anxiety and change. It implies trust and feeling secure in relationships with others.

INCLUSION

Is about being or bringing the person into the social world, not just physically or verbally, and making them feel part of the group, welcomed and accepted.

OCCUPATION

Being involved in an activity that is meaningful to the person, and which gives them back a sense of control over the world around them. It allows the person to feel that they have an impact on something that is done, and the way it is done.

IDENTITY

Is about knowing the person, what they feel about themselves and the way they think. Having a sense of continuity with the past, and that their life story is maintained, whether by themselves or others.

KNOW IT

Educate yourself and others. Understanding dementia isn't only about diagnosis and being able to identify symptoms. But reducing stigma and knowing how to respect and respond to the needs, will and preferences of people living with dementia.

KNOW IT

The person-centered, rights-based approach challenges us to focus less on what we do and more on the way we do it. By supporting peoples' needs, maintaining their personhood and well-being, we'll promote their Human rights. It is important to look at the way we interact with the person living with dementia, and ensure that we do so in an authentic and safe way – what Kitwood called positive personal work.

MEETING THE PSYCHOLOGICAL NEEDS OF PEOPLE LIVING WITH DEMENTIA

The following are different types of interactions that Kitwood described as a way of meeting the psychological needs of people living with dementia and how we can promote it in our everyday practice through simple but empathetic gestures.

- **RECOGNITION**
- **NEGOTIATION**
- **COLLABORATION**
- **PLAY**
- **TIMALATION**
- **CELEBRATION**
- **RELAXATION**
- **VALIDATION**
- **HOLDING**
- **FACILITATION**



KNOW IT

1 RECOGNITION

Address/greet the person by the name they prefer. Maintain eye contact during conversations

2 NEGOTIATION

Support the person to choose what they want to eat, wear or do at a given time

3 COLLABORATION

Doing tasks together with the person, not for the person (e.g. Support them dress themselves no matter how long it takes)

4 PLAY

Support the person to engage in spontaneous and self-expression activities (e.g. painting using their hands, not the brush)

5 TIMALATION

Give the person the opportunity to engage in activities that stimulate the senses and are not cognitively demanding (e.g. massages, aromatherapy)

6 CELEBRATION

Not only celebrating the person's birthday and significant dates (e.g. wedding anniversary), but also recognizing, supporting and joining in with something the person is doing (e.g. clapping and smiling while the person sings)

7 RELAXATION

Support the person to have a relaxing environment and moments, alone or with others (e.g. listening to music, sitting on a bench in a garden)

8 VALIDATION

Being empathetic and accepting the reality of the person, even if it makes no sense (e.g. hallucinations)

9 HOLDING

Providing security and protection when the person is anxious, staying close to them, holding their hand and showing empathy and affection towards what they feel

10 FACILITATION

Support the person to engage in tasks that they cannot do alone, supporting them only when necessary (e.g. handing the hairbrush to the person, and waiting for them to start and finish brushing their hair)

11 CREATION

Person with dementia starts singing or dancing, and invites those around them to join. A person living with dementia begins to take care of plants, removing old leaves.

12 GIVING

A person with dementia offers to help with a certain task. A person with dementia wants to offer something to a carer.

Kitwood also identified 2 other types of interaction, which unlike those previously described, come from the person living with dementia, that are spontaneous and directed to those around them:

KNOW IT

DESIGNING AN INDIVIDUALISED CARE PLAN

For these interactions to become routine for people that provide care to people living with dementia, e.g. in day care centers or residential care facilities, it is essential that an individual care plan is defined for each person. All professionals involved in the provision of care direct or indirect to people living with dementia, should be capable of incorporating information about the person in their care plan.

They should also be capable of facilitating and providing support so that they can engage in meaningful activities that provide well-being and promote positive, quality relationships. The creation of the individual care plan should be carried out in collaboration with family members, friends and or close caregivers, so they can contribute to the person's life history, interests, opinions and routines.

Given the limitations and changes caused by the different types of dementia, which affect different cognitive functions, it is essential that carers use different strategies in order to get to know each person in depth.



KNOW IT

LIFE HISTORY

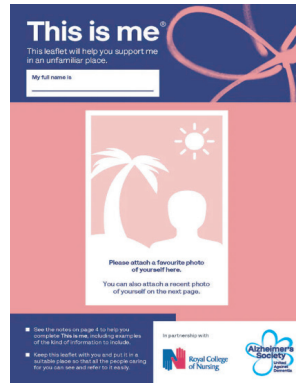
Below we share some practical examples or support strategies related to the person's life story:



ALL ABOUT ME

Alzheimer Society of Canada

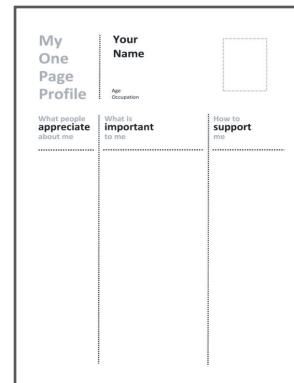
[See More](#)



THIS IS ME

Alzheimer's Society

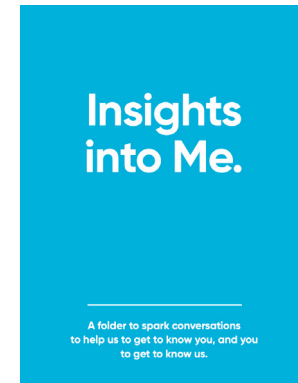
[See More](#)



ONE PAGE PROFILE

Person-Centered thinking with older people

[See More](#)



INSIGHTS INTO ME

My Home life

[See More](#)

PROMOTE IT

Learn more about Dementia and Human Rights and how you can influence and advocate for them. The PANEL Principles, endorsed by the United Nations, provide a framework to put a HUMAN RIGHTS-BASED APPROACH into practice and ensure real change for people living with dementia.

PROMOTE IT

SUPPORTING PARTICIPATION AND DECISION-MAKING

Adopting a human rights-based approach ensure people living with dementia have a voice and the opportunity to be involved in their own care. It is essential that carers don't just focus on what a person cannot do, but understand that this is often a consequence of a person's environment that has not been adapted for them and so limits or prevents them from participating actively.

The ability to make decisions cannot be seen as "all or nothing". It is up to everyone, whether social services, health services, or public services, to ensure that people living with dementia can be supported in decision-making, and that the focus is placed on their current capacities, always assuming that the person is capable of making decisions. This and other principles that we will describe below, should always be the basis of any interaction / situation that involves a person living with dementia in making decisions:

1 Assume capacity

Assume that the person has the capacity to make a decision on the matter at hand at the time the decision needs to be made.

2 Support the person

Provide as much support as possible so that they can make their own decisions.

3 Respect any seemingly unwise decisions

The fact that a decision seems unwise does not mean that the person does not have the capacity to make it.

4 Do not intervene unless necessary

Intervene only when it is necessary to do so, taking into account the person's current circumstances and capabilities.

5 Minimal intervention

Implies adopting an approach that minimizes restrictions on the person's rights and freedom of action;

- Consider first; dignity, bodily integrity, privacy, autonomy and control, over financial matters and property,
- Be proportionate to the importance and urgency of the matter on which a decision is to be made,
- Be as limited in duration as possible, taking into account the person's individual circumstances.

6 Valuing wishes and preferences

Always consider the person's known wishes and preferences.

7 Consider the perspectives of others

They may be family members and/or significant friends of the person living with dementia.

8 Consider the urgency of an intervention

Does the decision need to be made immediately or can it wait?

9 Use of information

We must only obtain information that is reasonably necessary to make a decision on the matter at hand.

PROMOTE IT

SUPPORTING THE PERSON

Here you can find simple suggestions on how you can facilitate and assist the decision-making process.

DECREASE THE NUMBER OF OPTIONS

Knowing the person's tastes in terms of drinks, instead of asking what they want to drink for lunch, ask if they prefer orange juice or water.

EXPLAIN CONCEPTS AND INFORMATION IN A SIMPLE WAY

Use simple language, with terms known to the person.

BE MINDFUL OF NON-VERBAL COMMUNICATION

Nodding the head can mean that the person is agreeing and understanding what is being said.

Frowning could mean that they don't agree or don't understand.

USE IMAGES TO EXPLAIN CONCEPTS AND MAKE CHOICE EASIER

Showing pictures of a beach or a cinema, so that the person can choose what they would like to do.

ALLOW TIME FOR THE PERSON TO PROCESS THE INFORMATION.

Wait a few minutes, and give the person an opportunity to ask questions.



PROMOTE IT

ENABLING, ENGAGING AND HOLDING EVERYONE ACCOUNTABLE

For changes to occur in the culture of providing care in organisations, it is essential that all carers have training, even those who do not provide direct care to people living with dementia.

It is important to ensure that everyone has continuous training on the subject of human rights, and also on the different types of dementia, and its symptoms, so that they can better understand the person living with dementia, and know how to support them. It is also important to give carers the opportunity to know the rights of everyone – users and employees – but above all, know how to respect and promote their rights in day-to-day person centred practice.

Additionally, it is essential to know the legal instruments that are in force in the country. All carers have a fundamental role in maintaining and pursuing this approach, and it is important that each organisation has internal policies, procedures and processes, safeguarding people's human rights. Organisations could also establish an advocacy and rights committee.

These measures will allow people to feel supported to recognise and report violations of rights, without fearing reprisals from anyone, and that they know there will be effective consequences, of which they will be informed.

They are particularly important when we realise that much of the disrespect for the human rights of people living with dementia is unintentional. That is why one of the principles of the HRBA is the assumption that caring is emotional work, and for this reason, the professionals who care for people living with dementia need to have their own personality respected.

This approach has benefits not only for people living with dementia – like better sleep patterns, decreased motor agitation and increase in well-being and quality of life – but also for carers, the main ones being:

- 1.** Increased confidence
- 2.** Better working conditions
- 3.** Increased job satisfaction and reduced turnover

PROMOTE IT

CULTIVATING A CRITICAL AND CHANGE-ORIENTED ATTITUDE

Change is not just about theoretical training. It implies that all carers have the ability to see another person's perspective, to present constructive criticism and to be open to change.

As carers, we should always be searching and evolving, and maintain a critical and reflective attitude towards procedures, using them as a tool for positive change and continuous improvement of the quality of care.

It is essential that the leaders in the organisation, are fervent defenders of care centered on the person, and that they are rooted in the philosophy and values of the organisation.

In this dimension, people in leadership play an important role in promoting a person-centred and rights-based approach:

- Model the actions expected by carers in their own interactions with people living with dementia, families and staff, and create supporting documents that not only explain concepts and principles in a simple and clear way, but also provides practical examples.
- Promote training and capacity building opportunities, and ensure that policies and procedures are consistent with a person-centred approach, and in accordance with defined procedures.
- Involve carers in decision-making, in order to promote change in the culture of care.

- Promote inspiring leadership.
- Encourage open and transparent communication with carers.
- Empower carers.
- Recognize and praise carers' practical approaches, their ability to reflect on actions and solve problems.
- Encourage carers to present solutions and strategies to improve the quality of life of people with dementia
- Conduct performance evaluations for all employees, and make the necessary changes.

It is advisable in this process to use an instrument to assess care practices for people living with dementia that allows us not only to regularly review our day-to-day practices but also to make changes. These are some of the tools we could use:

- Dementia Care Mapping (DCM)
- The VIPS Framework
- The "Feelings Matter Most"
- Person-centered Care Assessment Tool

PROMOTE IT

CHALLENGES AND A NOTE OF HOPE

Albeit that it is nearly 80 years since the Universal Declaration of Human Rights was adopted by the United Nations in 1948, the challenges to implement a global standard remain today. Legislation alone will not be adequate to safeguard the protection of the rights of people living with dementia.

Applying specific human rights based approach for people living with dementia will strengthen, educate and support advocacy activities. In the context of organisational transformation, “successful cultural change efforts connect with people through meaningful conversations, capture the hearts and minds of people around a shared purpose and support them to behave differently to deliver desired outcomes” (HSE).

Culture impacts everything we do in any organisation and is shaped by people and how they behave. Before implementing any change it is essential to understand the key areas for change to increase the chances of success and create the conditions for change.

In other words people need to understand:

1. Why there needs to be a change
2. How to prepare for change
3. The desire to change
4. The support needed to change

Elements of culture need to be considered in the context of visible and non-visible elements or “The Iceberg” above the waterline and below the waterline. In organisations the visible elements of culture include strategies, policies, regulations, and structure. Non-visible elements include beliefs, understandings, values and shared assumptions.



Creating the conditions for change and creating readiness will help address any challenges to implementation of a human based rights approach for people living with dementia. Change must be embraced at all levels but must be driven through effective inspiring leadership.

Build a coalition of people to support the change. Engagement and Networking to gain the insights and experiences of people living with dementia, carers, and healthcare workers is a valuable approach. Providing a platform to share personal experiences will support behavioural change efforts. Use of evidence, narratives and stories are powerful levers to influence change.

Finally, people need to understand WHY change. Connect with people by focussing on a shared compelling purpose: people with dementia should be treated with dignity and receive care and support that is based on individual need, rather than assumptions about the condition.

This platform will provide you with the tools required to begin meaningful conversations, create a shared purpose and support healthcare providers to advocate a human rights based approach.



GETTING CARE RIGHT MATTERS

A Real Life Experience

SAINT JOSEPH'S SHANKILL EXPERIENCE IN IRELAND

Theoretical knowledge can give you a deeper understanding of a concept through seeing it in the context of understanding the 'why' behind the idea. Our experience teaches us how theories are put into practice, in an imperfect world.

The Dementia Right Project has provided us with ideas and inspiration to change our approach to ensure a rights-based approach when caring for people living with dementia. But can this work in an imperfect world? Yes. We want you to See it, Know it, Promote it. Just like Saint Joseph's Shankill in Ireland.

Saint Joseph's Shankill is the largest dementia specific residential care home in Ireland and leads the way in dementia care. They have transformed from a traditional style, medical modeled nursing home into six new homes or 'lodges' as they are known. This was both a cultural and environmental change.

The first change happened to the environment because of regulatory requirements overseen by the Irish healthcare regulator. The regulator; Health Information and Quality Authority or HIQA; advised that the environment was unsuitable, as it did not support the privacy and dignity of residents. In order to maintain the nursing homes registration, HIQA directed that there had to be change to the open plan 8 bed shared space / unit, into one or two bedroom

spaces and also the open accessed bathrooms should be made private. This provided a unique opportunity to reevaluate the entire environment and what would work best for people living with dementia.

Saint Joseph's was a large open plan centre, which was purpose built for frail elderly, and was seen as 'state of the art design' in its time (1994) but by 2012 it was completely unsuitable for people living with dementia. [See some pictures](#)

Basically, there were two large open areas, each with 3 corridors where the bedrooms and bathrooms were situated. Each of these large areas had one small open plan sitting room and one large open plan dining room catering for 30 people. The two areas were then connected by an even larger 'communal area' (which included a chapel space) and this communal space served as the 'activities area' during the day. Essentially, 60 people at various stages of dementia shared one big living space.

They thought we had an accessible environment and a space that enabled participation; but the flooring, the shared open space, with nothing to occupy people, was all wrong. There was no possibility of 60 people taking part in everyday meaningful activities together.

So a remodelling building project began. [See some pictures](#)

The second was a culture change in care involving the introduction of a new model of care for people living with dementia. The model of care adopted was called the Butterfly Approach ©.

The Director of Nursing, who had a special interest in dementia care, had been researching different models of care looking for best practice for people living with dementia. She was inspired, by a talk by David Sheard (the founder of Dementia Care Matters) describing the evolution of Dementia Care Matters (DCM) and the genesis of the Butterfly Approach. This is where the vision for change began.

[Watch David Sheard visit Saint Joseph's Shankill](#)

Today, DCM is now known as [Meaningful Care Matters.](#)

You can find out what the Butterfly Approach© is all about [HERE.](#)

People form the culture and the culture is what is hard to change. To care for people living with dementia in the best way possible it means changing from being task orientated to going with the flow. Removing uniforms, nurses' stations, drug trolleys and disguising institutional or medical equipment was imperative to achieving a homelike environment. A home has to have a heart and it is all about the people who belong to the home, people living, working and visiting.

Of course in a nursing home there will always be a certain amount of things that have to get done every day, but they can be done at person's own pace and

according to how they want it. No one size fits all e.g. Mealtimes – breakfast when a person wakes up naturally, meals take as long as the person chooses. People can serve themselves like they would at home instead of being 'served' like in a restaurant or hotel. They are 'at home' and not in a hotel or restaurant.

The team at Saint Joseph's cannot change the devastating effects dementia has on people and their families. But they can and have changed the way they care for people. They have a compassionate and passionate team, that ensure that people receive the best care possible. They understand them and the people they are, they allow them the time and space to express themselves and their needs and their feelings.

They understand the challenges and know that change is not always easy. Being a part of Dementia Right Project has enabled the team at Saint Joseph's Shankill to share their knowledge; They Saw it, Knew it, and now are Promoting it. You too can be the change you want to see. See it, Know it, Promote it!

Saint Joseph's Shankill is an award winning and accredited Meaningful Care Matters; Butterfly Home©, it is the largest dementia specific care home in Ireland. You can See and Know that this can work when the commitment, leadership, and passion for person centred, rights based care for people living with dementia is championed. Below framed by Dawn Brooker's VIPS we describe real scenarios at Saint Joseph's Shankill

SAINT JOSEPH'S SHANKILL HAVE ADOPTED THE VIPS TO UPHOLD A HRBA EXPRESSION IN THEIR CARE HOME IN IRELAND

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VALUE

Value people living with dementia and the people who care for them; promote their rights and citizenship regardless of age or cognitive impairment.

- People's Life Stories are developed with them and their families and become the central part of their care plans.
- Care plans are written in the first person, using I and me rather than 'they' or 'them'.
- Advanced care planning is in place for everyone in accordance with the person's will and preferences.
- Families and friends are valued and welcomed to Saint Joseph's at any time, just like in a person's own home.
- We removed or disguised any 'institutional' or 'medical' equipment.
- Staff do not wear uniforms or wear name badges.
- We advocate for each person, locally, nationally and internationally – being a part of Demright Project has given us a chance to represent the people in our care living with dementia.
- We removed all forms of restraints; no bed rails, lap belts, or physical restraints are used. A positive risk taking approach has been adopted throughout the care home.

EXAMPLE:

One lady, who was a model and dancer in her earlier life, could no longer walk or talk and was confined to only a few steps. One day we fitted some red high heeled shoes to her feet. Her eyes lit up and she lifted her feet in the air showing off her beautiful legs, then with assistance from the staff she walked across the room in the heels, her smile said it all. She was truly being her real self in those moments.

SAINT JOSEPH'S SHANKILL HAVE ADOPTED THE VIPS TO UPHOLD A HRBA EXPRESSION IN THEIR CARE HOME IN IRELAND

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INDIVIDUALITY

Treat people **individually**. Appreciate that all people living with dementia have a unique history, personality, physical and mental health, social and economic resources and that these will influence their response to the neurological disorder.

- People don't live in 'Medical Wards' or 'Units', they live in homes.
- Through a remodelling project Saint Joseph's created 'lodges' where people at the same stage of their illness live together.
- People can get out of bed when they like, there is no set time for breakfast.
- There are no physical restraints used in Saint Joseph's, no bed rails or lap belts for example. People are allowed to move freely around their home.
- People have their own likes and dislikes, so they can take part in whatever activities they want.
- People are always given the choice of what they would like to eat and drink; and they are asked in a way that they understand.
- People's personal belongings are displayed in their homes to promote familiarity and enhance their individuality. Family photographs are displayed in the living areas.
- Each person's life story is brought to life in their life story box filled with items to remind each person of their lived experiences and inspire feel good memories.

EXAMPLE:

A man that lived with us, was a passionate motor cyclist before the onset of his illness. Unfortunately he was very young when he developed symptoms. As often as we could we helped him put on his protective leathers and his motor cycle helmet, and then brought him out on our triobike (an electric bicycle that allows two adults to sit in the seat at the front of the bicycle).

On these outings he could still experience the feeling of freedom, exhilaration and being out in nature, although not at the same speed as a motor cycle!

SAINT JOSEPH'S SHANKILL HAVE ADOPTED THE VIPS TO UPHOLD A HRBA EXPRESSION IN THEIR CARE HOME IN IRELAND

<p>V I P S</p>	<p>P</p> <p>PERSPECTIVE</p> <p>Look at the world through the perspective of the person living with dementia, recognizing that each person's experience has its psychological validity, that the person with dementia acts according to their perspective and that empathizing with this perspective has great therapeutic potential.</p>	<ul style="list-style-type: none">• We reach and connect with people through the senses focussing on promoting and enhancing positive feelings and emotions.• We define areas / spaces / seating through research based colour contrasting, focussing on the difference between the Light Reflective Values (LRV) of the areas we want people to notice.• Rooms are filled with lots of items to interact with and to discover, so people can rummage through boxes and 'be busy'.• We have installed sensory equipment and provide care through the use of different items to assist us to give people experiences to enhance their senses, sight, smell, touch, hearing and even taste.• Experiential / Interactive learnings for staff – moving staff in wheelchairs without telling them, blind folding staff while they are assisted to eat a meal, wearing of glasses that give the perception of impaired vision, all so that the team can put themselves into the lived experience of someone living with dementia.
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EXAMPLE:

One of our nurses creates an autumnal theme in the lodge he works in at that time of year. He collects bags of autumnal leaves, brings them to work and then scatters them across the floor of the living room, kicking leaves in the air, crunching them under foot and letting the residents hold, smell and scrunch the leaves themselves. Everyone living in his lodge can still experience a real autumn day through their senses of sight, sound and smell, connecting them to their own autumnal memories.

SAINT JOSEPH'S SHANKILL HAVE ADOPTED THE VIPS TO UPHOLD A HRBA EXPRESSION IN THEIR CARE HOME IN IRELAND

V I P S	<p style="text-align: center;">S</p> <p style="text-align: center;">SOCIAL ENVIRONMENT</p> <p>Recognize that all human life, including that of people living with dementia, is based on relationships and that people living with dementia need a rich and diverse social environment that can both compensate for their deficits and provide opportunities for personal growth.</p>	<ul style="list-style-type: none">• Six Lodges were created inside the existing footprint of the nursing home, each lodge accommodates people living together at the same stage of dementia.• Everyone is encouraged to get up and dressed every day to participate in the comings and goings of daily life of the lodge.• Development of a robust volunteer programme, so that volunteers can come and support the team to create meaningful connections with the people living at Saint Joseph's.
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EXAMPLE:

One of the people who lives at Saint Joseph's is from Germany and as her illness has progressed, she is speaking more and more in her own language of German, rather than in her adopted English. Now she enjoys a zoom call with a volunteer who speaks in German with her every week. Her sense of self is embraced and supported.

One of the day care club members, is a passionate opera "aficionado" and shares her passion with the other club members (all people living with dementia). She has made great friends with one of our talented volunteers, who brings in his classical music collection every week and not only plays the music but gives a talk about each piece. He now spends the time when he is not volunteering with us, sourcing the obscure records that our opera buff suggests to him. Her family are so grateful to him for his enthusiasm, and they both have made new friends through a shared passion.

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This Guidance has been informed by “PANEL” approach to Human Rights-based policy and practice, endorsed by the United Nations, consistent with the Global action plan on the public health response to dementia 2017-2025, the Universal Declaration of Human Rights and the Convention on the Rights of Persons with Disabilities.



GETTING IT RIGHT!

Guidance on a Human Rights-Based
Approach to Dementia



SEE THEIR RIGHTS

See the person as an individual, not the dementia. We all have our own likes and dislikes, our own life story, which tells us more about who we are than a diagnosis does.

KNOW THEIR RIGHTS

Educate yourself and others. Understanding dementia isn't only about diagnosis and being able to identify symptoms. But reducing stigma and knowing how to respect and respond to the needs, will and preferences of people living with dementia.

PROMOTE THEIR RIGHTS

Learn more about Dementia and Human Rights and how you can influence and advocate for them. The PANEL Principles, endorsed by the United Nations, provide a framework to put a HUMAN RIGHTS-BASED APPROACH into practice and ensure real change for people living with dementia.



PARTICIPATION



ACCOUNTABILITY



NON-DISCRIMINATION
AND EQUALITY



EMPOWERMENT



LEGALITY

