WHAT IS THE Purple Bicycle PROJECT?
The Purple Bicycle Project is a step by step way of helping our most vulnerable elderly people living in residential settings to feel they belong. To be included you just need to be in the room; to belong you need to be missed if you are not there. The approach enables a sense of belonging by sharing stories, lifting spirits and encouraging hopeful attitudes.

The Purple Bicycle Project gives the person with dementia, carers, relatives and friends an opportunity to review and sustain relationships that are meaningful and sincere.

The Purple Bicycle Project is a person centred spiritual care resource developed by Prof. John Swinton and Dr. Harriet Mowat at the University of Aberdeen and funded by the United Kingdom Arts and Humanities Research Council.

It brings together caring practices that are often found individually within organisations that care for older people. Its unique contribution is that these practices are presented as a linked and coherent expression of care and concern for the spiritual lives of people with dementia.

The Purple Bicycle Project consists of a purposeful six step process which we have called a journey. This journey is travelled by people with dementia alongside those who love and care for them.
WHY Purple Bicycle?

The Purple Bicycle suggests the idea of movement, change and journeying together towards a new place where we can all enjoy and delight in life.

WHO IS THIS RESOURCE FOR?

The Purple Bicycle Project is a resource for all. It is a resource for everybody, not just for those who belong to a Faith Community. As such, it can and should be used as part of daily care practice rather than an additional “activity” for people interested in “such things.”

This version of the resource has been designed primarily to support people with established dementia. By this we mean people who are beginning to lose their verbal ability to tell their story and who need others to help them to tell their stories well.

The resource would also be helpful for people who have other conditions that are causing them to lose their verbal ability to tell their story.
All people with dementia are worthy of spiritual attention and we know that as the disease progresses attending to people’s spiritual needs becomes more complex and requires more time and watchfulness.

“Waiting with” and “being alongside” people are acts of spiritual care. These spiritual care practices have meaning and purpose in that they form the basis of compassionate relationships one with the other.

Living in the present moment is a skill and a gift that is central to caring with and for people with dementia.

THE PURPLE BICYCLE PROJECT draws on such practices to provide a structured approach that helps all of us together to recognise and respond to the needs of people living with dementia.

Person centred care is now a key aspiration of health and social care services and organisations. This can only be accomplished if compassion and dignity are encouraged. Spiritual care is a vital part of person centred care.
WHAT IS DEMENTIA?

Dementia is first and foremost a profound human experience that happens to people who are valued and have full lives. In medical language it is described in terms of a clinical picture associated with brain disease. This picture consists of altered cognitive function; the brain changes. This includes changes to memory, together with changes in behaviour and social functioning. The brain disease concerned includes things such as senile plaques and tangles, and/or blood vessel disease which build up as the brain ages and which accompany loss of brain cells over time.

There are different types of dementia which manifest themselves in different ways. Dementia is more common in the over 65 age group but can be found in younger people. The specific cognitive changes can include memory, attention and language. These changes differ depending on which part of the brain has been damaged. The symptoms and behaviours change as the disease progresses. Different skills and abilities and lifelong habits remain whilst others are distorted and changed by the condition.

WHAT IS IT LIKE TO HAVE DEMENTIA?

But dementia is not only a clinical condition. It is a meaningful experience that occurs in the lives of important human beings. People with dementia are often frightened and confused by their symptoms. They struggle to make sense of what is happening to them. Researchers are now beginning to make a bit more of an effort to find out what it is like to have dementia by talking with people who are living with dementia. People at different stages of dementia are quite able to express their feelings given the right environment. They say that they know that something is happening and they try to find new ways of being themselves which accommodates the changes. Sometimes with the best intentions those close to the person can be overly protective and society can limit potential by being over cautious about risk. People with dementia can be very stressed by the illness and sometimes this stress is seen as part of the illness rather than a consequence of it.

One of the important jobs for those caring for people with dementia is to try to understand the individual experience and the impact this is having on the individual. This requires the building of a relationship with the person with dementia. Building such relationships is central to spiritual care.
WHAT IS SPIRITUAL CARE?

Spiritual Care involves developing a genuine relationship between individuals within which there is an acknowledgement that the clinical picture of dementia is not all that can and should be known and that human lives are mysterious. There is more to living well than simply caring for our bodily needs. Spiritual care acknowledges the presence and importance of such things as joy, hope, meaning and purpose as well as the reality of disease, suffering, disappointment and death.

Spiritual care is driven by a belief that life is purposeful and that shared human experiences and relationships is one vital way of living with purpose in the midst of a very difficult condition. Spiritual care implies that we are all the same; we need meaning and purpose in our lives. And yet, whilst we are all the same at one level, our lives are uniquely lived. Spiritual care often acknowledges the importance of relationships, community, mystery, wonder and for some, God. Spiritual care is therefore essential to all of us, whether or not we have any kind of formal religion or faith commitment. Spiritual care is the basis of our relationships, one with the other.

The Spiritual task is to offer friendship, comfort and hope to each other in ways that are meaningful to the individuals concerned.

WHAT IS IT LIKE TO LIVE IN RESIDENTIAL CARE?

When people move into residential care it is often as a result of some kind of crisis. Although it is much preferred to have a planned move into residential care, very often the move happens quickly as a consequence of unforeseen circumstances.

The older person with dementia, already confused and distressed, arrives in an unfamiliar setting and is required to settle into a completely different way of life. Communal living is never easy. Ask those who have lived in a Kibbutz, a monastery or a commune. So at a moment when you are most uncertain about yourself and your abilities; at your most vulnerable, you are asked to set up new relationships with strangers in a new setting which is not of your choice. You are told that this is your home. No matter how good the care, how safe the environment, how nice the food, how pleasant the staff, the older people would rather be at home. Residential homes are reluctant communities.

This is confounded further by that the idea that care homes are the same as an individual’s own home. Living in a residential home is inevitably a different form of living. What the residential home can be and very often is, is homely and welcoming and acknowledging of the difficulties of creating community and a sense of belonging in these circumstances.
WHAT IS IT LIKE TO WORK IN RESIDENTIAL CARE?

Care staff are, on the whole, extraordinary people who are dedicated to the people they work with and who go extra miles to help support their care home dwellers. However, sadly, care staff tend to be negatively labelled by the bad press which is generated by the poor behaviour of staff in a tiny minority of homes. On top of this they are often not well remunerated for their pains.

The work is hard physical work and at times emotionally very taxing. Staff are dealing with the rough end of ageing and death. Although staff would like to spend more time sitting with and being with the residents, there is precious little time to do this. Often, staffing levels are a challenge. There is also a pressure to record and form fill and to be seen to be working hard. It can all become a little disheartening.

THE Purple Bicycle STEPS

This resource is structured as a series of questions followed by actions which make up six “steps”.

Each step consists of a question and an action.

The purpose is to build up a picture of the spiritual lives and needs of the person with dementia step by step. This picture is formed through gathering appropriate people to engage in storytelling and making a spiritual map from which an action plan is developed and followed through.

THE PURPLE BICYCLE PROJECT gives the person with dementia, carers, relatives and friends an opportunity to review and sustain relationships that are meaningful and sincere.

The intention is that the journey through the steps supports the person with dementia, the staff and the relatives in finding ways of communicating and supporting which are sustainable and enjoyable for all.

The journey itself is the important focus.
HOW HAVE OTHERS FOUND THIS RESOURCE?

We have tested this process carefully in different settings where people with dementia are living. We found that staff, relatives and friends feel supported because they are able to engage in something tangible with someone with whom past ways and patterns of conversation and social interaction is no longer possible. They have been able to find new ways of being together.

WHAT HAPPENS NOW?

We also found that incorporating this work into the care plan turns it into something that is done regularly and considered "normal" caring practice.

If you are interested in learning more about this project or being trained as a purple cyclist facilitator please refer to the letter accompanying this booklet.