

Coordinated eCare

Better home care for people with dementia through ICT-enabled information sharing in Dublin / IE

Maura McBride is a 76 year old living alone; her husband passed away three years ago. She has two children, one daughter Bernie who lives nearby, and one son who lives abroad. Two close friends live in the area as well, a medium-sized town in the south-west of Ireland. Maura has middle-stage dementia which is deteriorating rapidly despite the use of medication. Her daughter comes in every day to check on her and spends a few hours cooking, preparing meals for the following day, clothes washing and making sure the house is in order. Three times a week she helps Maura take a shower and exercise. Maura and her daughter are supported by Patricia Delaney, a part-time care assistant employed by the Alzheimer Society of Ireland. This is a voluntary organisation with an extensive national network of regional offices and services that aim to provide people with all forms of dementia, their families and carers with the necessary support to maximise their quality of life. Patricia has three clients that she supports two hours a day per visit. She fills out a logbook every visit detailing time arrived, time left, activities carried out inside the house and outside the house, and any observations. The logbook is left in the house for the family carer to keep track of and a copy is sent to Jane Murphy, the care co-ordinator working at the Alzheimer Society. For about a year Maura has a full telecare package installed, including a base unit, pendant alarm, smoke alarm, three movement detectors, heat sensor, property exit sensor, CO detector, flood detector and fall detector. The package is provided and maintained by Emergency Response Ltd, a for-profit alarm service provider offering a 24/7 service nationwide with over 35,000 clients. Over the last three months, Maura has consistently left the house on Friday nights at midnight. The front door of the house has not always been alarmed due to the family carer forgetting to set the alarm. She has been identified as missing on a number of occasions and found by the local Gardaí. As she deteriorates she has lost the ability to remember where she lives and has consequently spent nights in the local hospital.

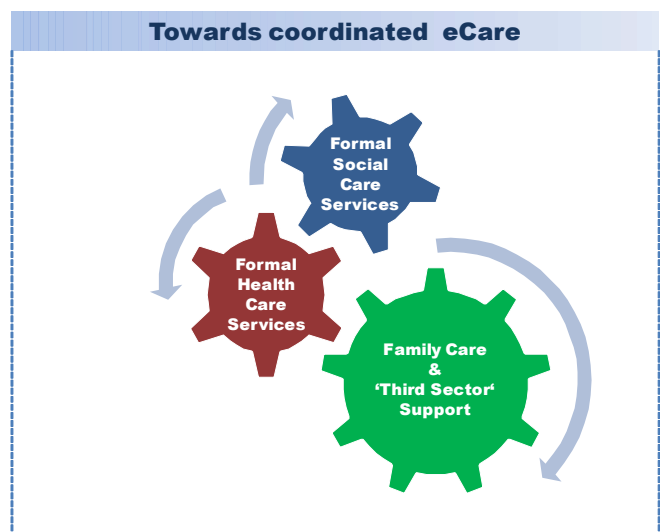
Maura's situation is not uncommon. People living with dementia in their own homes often depend on the support by family carers and professionals from different domains. As their situation deteriorates, there is an increasing need for cooperation and information sharing between the different parties involved, the telecare packages and monitoring systems must now also aim to assist in this increasing need for cooperation and information sharing.

The need for coordinated eCare

When it comes to supporting older people living in the community, today's reality is still characterised by fragmentation in current service provision resulting in disjointed and patchy support. The potential of innovative ICT solutions for supporting older people in living independently remains underutilised, and possible quality of life improvements are not being achieved. This situation has negative impacts on the economic sustainability of welfare and healthcare systems. It is widely acknowledged that models of formal support provision for the older population need to change, to reflect budgetary pressures and demographic changes, including different ways of accessing formal carers and co-ordination of informal care. This creates obvious needs for integrated means of communication and the supporting technology.

The potential of technology to support people with dementia and their family carers has been recognised by the Alzheimer Society of Ireland, a national voluntary organisation with an extensive national network of regional offices aiming to provide people with all forms of dementia, their families and carers with the necessary support to maximise their quality of life.

The organisation has begun to roll-out telecare support packages for clients who can be expected to benefit from such technology. The monitoring and organisation of response to alerts from the telecare support package is provided by a third-party provider, Emergency Response Ltd. About 100 families have received an enhanced telecare package across three counties in a specified region of Ireland. An evaluation carried out in 2009 generally proved positive. However, it has highlighted a number of areas where integration of current services could be improved, in particular when it comes to using telecare data generated by home sensors in a more targeted manner. In the framework of the **INDEPENDENT** initiative, a three year project co-funded by the European Union's Competitiveness and Innovation Framework Programme, the Alzheimer Society of Ireland has set up an ethically and robust communication system that allows for alarm usage of the client to be shared in a way that improves their experience of the service and allows for early intervention from the care service provider.



The service concept

People with dementia and their carers receive an enhanced telecare package that not only supports them in the community, but is also set up to alert the key professionals involved in their care to their changing needs. An accident/incident occurs involving the service user, the telecare equipment creates an alert, the operator at a monitoring centre takes the call and confirms that it is a Red Flag Event, e.g. a fall. Adequate response is organised by the operators according to a pre defined protocol. Beyond this, a new communication portal allows the alarm centre system to be capable of extracting an 'escalation protocol' making the information accessible to other parties involved in the care process, e.g. a Care Coordinator at the Alzheimer Society. The Care Coordinator logs into the portal to view details of the Red Flag Event and all associated subsequent actions and events. Beyond this, the care coordinator automatically

derives an 'event history' from the assisted person's telecare client record to identify any pattern potentially requiring adaptation of the current care plan, and adapts the care plan respectively. For example, over a period of three weeks, three falls occur during at night at a similar time as the service user left the bedroom to use the bathroom. On analysis of the "event history" the care-coordinator makes a home visit with the carer to assess any possible cause/solution to these falls. After this follow-up, the care plan is changed to include an additional duty of the carer to ensure a nightlight in the hall remains on at all times, this is also discussed with the service user and the family as a means of preventing falls in the dimly lit hallway during the night.

Service benefits

The example above illustrates the benefit of timely sharing of information between the monitoring centre and the care provider as well as the family. As shown by the 2009 evaluation of telecare provision, the clients of the Alzheimer Society benefit from the reassurance that telecare can bring to both carers and to people with dementia, and other benefits such as accident prevention, increased independence, peace of mind etc. Potential benefits are expected to increase by further development of the standard telecare package in terms of the secure and robust communication system that enables the 'telecare service' to run smoothly and ensure that key information is shared in a timely manner with the key stakeholders involved in the care of the person with dementia. An in-depth evaluation of the latter aspect is currently prepared: a dedicated pilot with about 100 users will begin towards the end of this year. The evaluation encompasses impacts on the cared for persons and their families, on professional staff and on the service provider organisation. This will be augmented by a cost-benefit analysis.

The evaluation is expected to show a number of specific benefits:

- The sharing of close-to-real-time information allows for better informed and more timely decision-making in terms of care planning and case management of vulnerable clients when risky or significant events occur. The long term advantage is that it allows for more detailed mapping of the deterioration in a client's condition.
- Easier access to relevant data ensures that the assisted person gets the appropriate care for her needs, and recognition of the limits of the family carer's ability to provide 24/7 care. ICT also allows for early intervention in situations of risk and prevents crises arising.
- An important medium-to-long-term advantage is the ability for the assisted person to remain living in her own home for as long as possible as is government policy in Ireland at present. This ability to remain living in their own home is due to increased levels of reassurance and support for the assisted person and family carers, as well as increased safety and security in concrete terms. The combination of reassurance and better care management significantly increases the assisted person's ability to stay at home.

"Pre- the INDEPENDENT Pilot there was no automatic connection between the monitoring system and the care provider and information received by the care provider about a service user was untimely and not easily traceable - the piloting of the new portal allows real time flow of information and proactive responses from the care provider"

Mary Connolly, Alzheimer Society of Ireland

- Systematic identification and redeployment of telecare packages that are no longer needed leads to better and swifter use of resources as it allows faster identification of available equipment.

ICT enabled service integration for independent living: the INDEPENDENT project

The quest for more integrated care is not new, but recently more opportunities for effective realisation have emerged. In particular, the appropriate application of advanced information and communications technology (ICT) can make a major contribution to this goal. The **INDEPENDENT** project sets out to develop and pilot an integrated set of ICT-enabled services to deal with a range to threats to independent living common to older people. By means of innovative usage of ICT, current “silos” in service delivery are broken down to allow for cooperation across all relevant sectors and participation of family members. To this end, **INDEPENDENT** pursues a dedicated programme of service process innovation complemented by adaptation of technology.

INDEPENDENT services are piloted at six sites across Europe, including Dublin (IE), Hull (UK), Milton Keynes (UK), Malaga (ES), Trikala (GR) and Geldrop (NL). These are adapted to the specific circumstances prevailing at each individual pilot site, e.g. current practices in health and community care provision. Apart from services that are directly delivered into older people's homes, so called organisation cooperation services at the "back-office" level are also addressed by the project.

The initiative has started in January 2010 and will come to an end in December 2012. To learn more about **INDEPENDENT**, please visit <http://www.INDEPENDENT-project.eu>.