

## Interviu su Rita Bencivenga, publikuoto Wired, vertimas į anglų kalbą ☐

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Complete translation of the article in Italian published on [Wired](#)

*I've always been involved in training and planning in the health and social sectors. Since 1988 I've been running Studio Taf, which carries out research and planning for the adult education sector. My priority, which I try to include in all projects, is promoting inclusion and overcoming discriminatory attitudes and practices.☐ My work doesn't focus on ICT, and I'm not a computer expert, but I use ICT to create and pass on knowledge and awareness. In 2000 I completed a university course on multimedia resources in E-learning, which showed me that it could be used successfully to train and update social/health workers and people working for NGOs. Since all our projects have their own web site, some have blogs and many involve online training activities, I believe it's essential to always use free software. Firstly, nearly all our projects are co-funded by the European Union, so it's about making the best use of public money. Secondly, I☐ think this approach should be used in any case, since shared wealth promotes the construction and exchange of knowledge and information to the full. Since I believe in the copyleft model as a whole, not only do we use free software, but all our project results and products are always in the public domain and can be used by anyone."*

**What tools can we use to "pass on knowledge and understanding"?**

The most recent example is the project we've been working on the past few months. "ELSA Empowering Lives, Supporting Affectivity" is co-funded by the EU's Lifelong Learning Programme (LLP), sub-programme KA3 ICT. We've produced short videos and pdf documents with the experiences of professional caregivers and relatives caring for frail elderly people, including people with Alzheimer's and various forms of dementia. The videos and files are now being distributed via the project's web site ( [www.elsacare.eu](http://www.elsacare.eu) ) as well as on Youtube and a Facebook page, "Elsa Care [Italiano]". This is a real example of user-generated content.

Within the partnership, we consciously avoided including experts on professional video production. We wanted to pass on the message that every one of us – professional caregivers and relatives – has a wealth of practical knowledge which we have gathered in our day-to-day lives, and this has a value for others. Anyone can make products like ours: you don't need expensive software. All you need is a few techniques, strategies, experience and the conviction that you can help someone else. At Studio Taf we've concentrated on selecting the content, helping choose issues which could be of use to a wider public and checking that they are compatible with the latest care procedures.

Do you think techniques, strategies and experience are enough? Don't you need a fertile ground too? Are people ready for this, in your opinion?

Seeing as we're talking about ICT and free software in particular, I think that some people are more than ready. Most elderly people in Italy aren't isolated. They have children, grandchildren and great-grandchildren. If their children are aged between 40 and 60, they're often familiar with internet; they use social networks, make their own holiday videos and upload their photo albums to Flickr. Not to mention grandchildren: people aged thirty, twenty or even younger, who, contrary to common opinion, do care for their grandparents and use the web to track down information and exchange knowledge.

The aim of the ELSA project isn't to promote social networks: we want to make contact with people who already use them. It might be a niche audience, but there are real benefits to be gained from having constructive, positive information.

We're inspired by the Anglo-Saxon approach, which is extremely practical. In Italy there's a tendency to concentrate on the negative aspects of the illness. Many of the sites, blogs and FB pages linked to Alzheimer's and dementia focus on giving the latest research and fund-raising news. Our approach doesn't deny the negative aspects, but we try to face the day-to-day

realities and find solutions and answers.

### **What are the positive aspects? And the obstacles?**

The main difficulties come from always working with foreign partners, and having to take account of needs and experiences which often differ widely from our own. Then there are the obstacles of our target group – adults, many of whom are over 60. People aged over 50-55 sometimes have a negative image of computers. They associate them with difficult times in their careers when the arrival of the computer created problems; sometimes their idea of computers no longer corresponds to reality.

In the past, many adult education courses focused on things like Bit, RAM and CPU, and this has created lasting damage.

Luckily, the arrival of social networks, lightweight laptops and, most importantly, touch-screen smartphones has completely revolutionised the sector.

Paradoxically, a person aged 75 who starts out by using an iPad has a head-start over someone aged 55 who thinks they need to know how a computer works before they can use it.

There are many positive aspects. In terms of ICT and free software, Web 2.0 is providing civilised society with undreamed-of opportunities to free themselves of the information monopoly. The monopoly certainly hasn't helped empower individuals and groups who are culturally, socially and economically vulnerable.

We can't predict what will happen in Italy, because we're only just starting out. The level of awareness and exchange of knowledge shown by people coping daily with the challenges of caring for those with Alzheimer's and dementia is a source of surprise and admiration. They are constantly reading and taking part in discussions on American, Canadian and northern European social networks.

An example is the online discussion groups for newly diagnosed patients. They share everyday experiences, offering friends and relatives advice and strategies for coping with behavioural problems and unrest when the environmental conditions are not ideal.

We compare these discussions to what we hear at our meetings in care homes and with relatives' groups and small NGOs. We believe that we have taken the right direction, even though it may take a little longer than we thought. Or perhaps not...