

# COMMUNITY LED LEADERSHIP

*'People die twice, first socially, then clinically.  
We must do more about the first.'*

## **An interview with Susan High, Community Development Coordinator at Strathcarron Hospice in Denny/Schotland**

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Susan High is Community Development Coordinator at Strathcarron Hospice in Denny/Scotland. She is the internal guide for the transformation from a traditional healthcare organization to a community-led organization, guided by ABCD (Asset Based Community Development). In 2013, the hospice first started working in a community-oriented way instead of investing solely in better service and care. Susan High on that beginning: 'We recruited and trained volunteer befrienders to support people living with life-limiting illnesses in their community. It was successful. People loved the connection. Carers enjoyed a break. GPs saw a reduction in consultations with people who were clearly lonely.... We discovered the power of reciprocity. The magic of human connectedness had become visible to us. We also began to understand that there is more to life than health, and that professionals supplement the community rather than the other way round.' (blog [www.nurtureddevelopment.org](http://www.nurtureddevelopment.org))

Since 2019, the Hospice has received mentorship for their community work from Nurture Development as a 'Learning Site'. This international organization, led by Cormac Russell, advances the development of community development in neighborhoods and districts worldwide from ABCD.

### **ABCD as a guideline**

"The hospice always had a strong person centred approach, but we didn't realise the potential of the community. We felt that professionals were the most important thing. The senior management have always been very supportive of my explorations for new ways of working.

In 2019 I attended a masterclass delivered by Cormac Russell, which provided me with language to articulate what I was doing. It really struck a chord, felt like coming home. As an ABCD Learning Site we received intensive support from Nurture Development. The corona lockdowns made community orientated work more important than ever.

An important guideline for managers and workers of the Strathcarron Hospice is to no longer decide and organize for people, but with and by people. The Strathcarron Hospice does this with a broad focus. They focus not only on the residents and their family and friends in the hospice, but especially on the communities in the village. From the realization that 80% of whatever is important for Hospice residents is available in these communities: participating in social life, building friendships and living meaningful lives with others, especially at this stage of their lives. But also offering each other comfort and support, sharing passions, being able to contribute, belonging.

### **Connecting Community Builders**

The Strathcarron Hospice team now includes community builders who initiate and support initiatives and projects that contribute to stronger communities. Such as connecting people with the same interests, finding and bringing community connectors together, facilitating community conversations, supporting initiators in realizing their idea and connecting them with other fellow villagers. There is also a neighborhood community connector who connects people who are involved in our "live your life" service. These people live at home in their community, but have often become isolated as a result of illness.

All kinds of great initiatives have arisen, such as a community cafe, people who collect litter together, a knitting club, choirs, correspondence during the coronalockdowns and contacts between school children and hospice residents. In the beginning, there was fear among employees that their work would no longer be important. Nurses were afraid of losing their jobs because we could no longer offer day services at the hospice.

In the past, care always lagged behind, community-based working was very new. In the beginning, the teams also found it difficult to see the importance of community-based working. You have to look very differently and much smaller than you are used to to see what changes as a result. If it turns out that it really makes a difference in people's lives, that it contributes to their well-being and happiness, employees will be enthusiastic to get started."

#### **Commitment from board and management**

"It was important that our board and management fully committed to it and embraced and promoted the shift from service delivery to involving people and communities, from individual care to community care, from for to by people. For the Hospice departments and the General Practitioners (GPs, treating, referring physicians) it was difficult at first to understand what we are doing. We are now often asked by other healthcare professionals whether we want to share our experiences with and knowledge about community development. Because its impact is becoming more and more visible. They see that we are building useful networks, that people's well-being is improving. Like a resident with lymphedema, a really painful swollen arm, who joined a choir that someone from the lymphedema team had started. That choir has a major effect on her well-being and health."

#### **Learning as a permanent part of the job**

"Make sure it's fun to learn! Since we have been consciously engaged in community development, learning from our own practice has become a permanent part of our work. Every Friday we have a learning conversation, always about practical experiences. We use the experiences of the employees of the past week for this. My most important role as a manager in those conversations is to mirror. I help them to see the impact of their work, the differences between traditional and community based work. But in fact they make the leap into the other way of working and only develop it further when they are ready for it themselves, you can't force that. They were quite afraid to work differently. You have to deviate from what you are used to, from the norms. It takes a lot of courage to do that.

It does not help to want to persuade or to teach. But to reflect how much people have already learned and put into practice. Telling practical stories can also help, but that too has only limited effect. What brings real change is when it has become their own stories, when they have

experienced it themselves. And then it's often about small changes, the trick is to see and name them. All those tiny steps. We also use the ABCD principles for internal changes, such as doing nothing without employees, asset-based, including, no preconceived plan, one thing leads to another.

It doesn't help to try to convince people. If there is one person who is a little braver than others, others can piggyback on it. For example, one of the nurses had the potential to work differently, but she didn't like it at all in the beginning. She felt that the switch would be impossible for her. It took a lot of encouragement before she took the first step. When she did and worked much more from the point of view of the residents' well-being, it felt like an enormous liberation for her to be able to work in this way.

We are now in a phase where you can see and feel the changes in people's well-being, the growth of the community. I often don't have to do more than encourage with a 'Go ahead!' Then you can almost feel the pleasure that people get from that. Just like the fun they have when they notice how different it turns out in practice. What we did next was to delete a lot of rules and parameters. Naturally, this required commitment from the directors and management. And that also required a lot of courage, especially in a clinical setting. In making the choices and changes in strategy and policy, senior management received support in the form of a mentorship from Cormac Russell.

### **Differences with the past**

“We used to be involved in communities, but community development was not an active part of our work. We are now working with Cormac Russell's 'lane model'. He compares the work in and with communities to a three-lane highway. The left lane is what residents can do best themselves. The middle lane is what residents and communities can do with a little support and the right lane is what agencies and organizations can do that communities cannot do themselves. That helps us to make the right choices in situations and not automatically do everything for people. In the past, it was always about the medical conditions. Now the patients have become persons. It is not someone's illness that is central, but the question of who and what are important in his or her life. And what someone likes to do and is good at. We used to have questionnaires to measure well-being. Now we have regular conversations, where those things come up naturally. And where we also ask what plans someone still has for the future and how he or she would like to be helped.

We work with many volunteers and have learned a lot from them. For example, we used to be very apprehensive about sharing something from our private lives. They always thought that fear was nonsensical. They just became friends with residents. Were not helpers but just did it for fun. There is always a lot of reciprocity in the relationships between residents and volunteers. They are therefore much more friend than buddy. And that is actually very natural. A strong guideline for us is not to make people dependent on us. As a nurse you are no longer central, you become less important. The focus of the work is more on getting to know people who play a role in the lives of people we are working with and on what is important to people themselves. An example: a resident needed a lot of care and often felt very bad. His passion was creative drawing, that was part of who he was. He had weekly care appointments with a nurse who always brought him great relief. When

he had to choose between this appointment and a creative drawing class, he chose the latter. That says a lot about what is important to people.”

### **Lesson for the Strathcarron Hospice**

“We have bundled our experiences from recent years in an evaluation report and we share it in a webinar, where CEO Irene McKie and Cormac Russell also talk about our lessons. Irene McKie also tells what we have learned in that webinar. For example, how enormous the potential of a community is. That it is up to the community itself to determine what is important to it. Not at the hospice. How important it is not to take anything from a community. That there is far too much medicalization and that communities can often meet a need better than a professional. That it is about neighbors helping each other, not organizing more volunteers.

How great the power shift is when a client is given the opportunity to actively contribute to the hospice, also to help from his or her talents and possibilities instead of just being helped himself.”

*The webinar and report can be found at [www.strathcarronhospice.net](http://www.strathcarronhospice.net), 'Putting community at the heart of the hospice movement'.*

*Interview: Birgit Oelkers/Plan en Aanpak, The Netherlands [www.planenaanpak.nl](http://www.planenaanpak.nl), July 2022*