



Developing Active Coexistence - A Way of Living and Working Together

What do we mean by active coexistence?

- Creating a community where people live and work together
- Involves social interaction – the more you interact with people, the more you coexist
- Actively accepting diversity and difference
- Involves the breaking down of barriers
- Sharing emotions
- Not seeing the dementia, but the person
- No hierarchy – shared control for all
- Facing challenges together
- Outward expression of positive and negative emotional freedom
- Equal and reciprocal relationships
- For people to have a life, not just to exist
- Involves identity – knowing each other
- Freedom to exist together in a safe, loving and warm environment
- To foster a collaborative and empowering sense of community
- Recognising people's strengths and ability to contribute for/within their community
- Everyone has a right to be themselves
- Inclusion – this requires change and innovation

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“Fundamentally, active coexistence overturns conventional passive relationships between ‘service users’ and those who serve them. It alters a model of services from a deficit approach to one that provides opportunities to recognise and develop people’s capabilities actively within their community.

Community means togetherness, where there is no ‘us’ and ‘them’. In essence community is people living and working together within the home. People are no longer seen as staff and residents, carers and service users, and the home, the centre of the community, is no longer seen as a care setting but a place for active coexistence” (Merevale House, 2010).

Community Structure

People need to believe and commit to the concept of active coexistence within the community. Everyone needs to do this – the cook, the cleaner and the administrator. The selection and recruitment of people working in the community needs to focus on personality and attitude, rather than qualifications. Such individuals are required to be *and* trained to be innovative, open to change and forward thinking.

Community leadership: Community leaders (formerly known as care managers, team leaders etc) must be accessible and approachable. They need to be seen to lead by example, facilitating the community's philosophy "on the floor" on a daily basis.

Everyone is of equal value. This is achieved through mutual respect for each other and one's living and working partnerships. It is important to recognise that everyone has strengths, acknowledging that we are all unique and diverse. It is through difference and diversity that a colourful array of skills can be embraced within the living and working partnerships.

Everyone has a voice and is heard. Every conversation between those living and working together is significant and not only has meaning, but is acted upon if concerns are raised (no matter how small). Formal meetings are only considered a small part of this process as the on-going verbal exchange between people is considered more important due to the need for a relaxed and informal environment.

Everyone in the community is required to have an awareness of each other's feelings and respond accordingly.

People working within the community are required to have a shared vision of responsibility for others and for their actions.

People are no longer seen as OR called carers/support workers, but community facilitators whose role is to provide opportunities and actively encourage people's capabilities.

Everyone within the community has a right to be themselves.

It is important to create and maintain partnerships between individuals, their families and external agencies as a means of constructing a sustainable and active community.

Creating an Active Community

An active community requires the removal of barriers. This means no uniforms; no separate toilets (for 'staff' and 'service users'); no separate cups; no separate mealtimes; no 'staff' rooms; no locked doors (an open door policy); freedom to access all living areas and gardens at all times; freedom to use the resources of the home, for example the kitchen.

It is important that people's rights and lives are not controlled by Health & Safety. Positive risk assessments are required to allow people to lead a normal life and exercise control over their own life and how things happen within their community. The opposite of which would be negative risk assessments which prevent people living their lives, placing restrictions on daily activities such as baking cakes and peeling vegetables.

An active community has no institutional activities or regimes. This means no drinks trolleys; no bath lists and people **do not have to** get up or go to bed at set times.

People are involved in the daily running of their community. This involves shopping, cleaning, washing up, cooking, doing the laundry.

People have a voice and are heard. As part of an active community this is achieved by active listening as well as responding to and acting on people's feelings.

It is important that everyday counts in as far as people are provided with opportunities for fulfilment.

Facing challenges together: This means responding to people's emotions whether it is providing comfort or hugs.

Supporting people with their personal challenges and seeking a solution.

An active community will discourage the use of antipsychotic drugs and seek alternative therapies such as massage, relaxation and sensory stimulation. It ought to be considered a passive approach to use antipsychotics as a form of control over behaviour. An active community must have a belief that people living within the community feel safe, emotionally free, have a purpose and are not bored. This can be seen as a means of preventing behaviours which are seen as 'being difficult', therefore reducing the need for the use of antipsychotic medication.

On-going improvement: It is important to constantly review and seek to improve the community. This ought to be carried out by listening to those who work and live within the community.

The Colour of the Community
It is crucial to create a domestic, age-appropriate, homely environment where people feel safe and free. This can be achieved by small, domestic-scale living spaces which will comfortably seat a maximum of 14 people (for larger living spaces room dividers may need to be used in order to achieve this).
Separate and bespoke communities must be created for (i) older people living with Dementia; (ii) younger people living with Dementia and (iii) people living with Alcohol-Related Dementia. Each group may have different outlooks on life, whether it be generational or otherwise and have the right to create their own community which is appropriate for them.
Seating must be comfortable with a mixture of sofas and chairs.
Background music is significant in order to create a lively atmosphere or aid relaxation. It is important that people choose the music they listen and dance to, depending on the music they like and how they feel at that moment in time.
Limited use of televisions. Unless there are specific programmes that people would like to watch, the use of televisions ought to be kept to a minimum. This is because people living in the community can find sitting in front of a television extremely boring and frustrating, often causing adverse effects.
Clutter is positive and is encouraged as this helps people feel comfortable and at home.
Rummage boxes need to surround the living spaces and be available for use. These are boxes which are full of sensory items and objects such as shoes, shoe polish, hairbrushes, a selection of fabrics, newspapers, magazines, soft toys etc.
Walls need to be decorated with sensory boards. These boards can be decorated with things such as feathers, lights, soft and rough materials.
Corridors need to be colourful, with interactive prompts and decoration. These include coat racks displaying handbags, scarves, coats, feather boas etc.
Each person needs to have a personalised room with their name displayed clearly on the door. It is useful to create a name plaque with pictures of each person's individual interests/hobbies – this helps people relate to their own space.
Bathrooms must not be clinical but warm and interesting. This can be achieved by appropriate use of colour and decoration to include seaside mobiles, shells etc.
Illustrative signs need to be used (subtly) to guide people to different living spaces. E.g. the sign for the lounge will not only say 'lounge', but have pictures of sofas etc.
No locked doors: Everywhere (even the garden) is accessible at all times.
The garden/outside areas must be used. In order for this to take place they need to be accessible and practical with good seating areas. Gardens ought to be as colourful and creative as the inside of the home. This can be achieved by planting raised flower beds and sensory gardens (such as mint, lavender, thyme etc). All members of the community are encouraged to develop and nurture outside areas where garden sheds are open for people to 'potter' in and out of.
There needs to be an upbeat and friendly atmosphere within the community, with busy and relaxed areas available for people to enjoy.
Friends and family ought to be considered part of the community and are actively welcomed. There must be no set visiting hours. Friends and family are allowed and encouraged to partake in mealtimes and the running of the home.
Limited use of mirrors: Mirrors can cause negative emotions for people.
Community Life
People within the community need to feel safe and supported, as they would at home with

their family. This is achieved by freedom of expression to love, laugh or cry and the creation of a relaxed environment which resembles a family home.

Daily life within the community is made up of very little or no routine. People are free to get up when they want and go to bed when they want, eat where and when they want, take part in activities when they want, make drinks or snacks when they want, etc. Arguably, this is a major shift away from a task orientated system and structure, but is key to creating an active community.

People living within the community come first. Tasks, for instance making beds, come last.

Everyone has a role to play within the community. It is important that all members of the community are involved in the daily running of the home – to provide occupation and purpose. Activities such as setting the table, washing up, cooking and cleaning are central to this belief, where the end result is not the focus, but the process itself.

Mealtimes are a social occasion where all members of the community eat together. Food discussion and pictures of meals are provided when individuals are choosing their courses from the menu. It is important that each menu has a minimum of three choices for each course and that the entire menu is changed each week. All menus are created by those living and working in the community.

Food needs to be available 24 hours-a-day. It is important that people can eat what they want, when they want.

Choice should underpin all that is said and done within the community. People need to be able to feel comfortable enough to outwardly express their likes and dislikes. This relates to all aspects of living from deciding what clothes to wear, food to eat, activities to do.

Living plans (previously known as care plans) need to be extremely detailed, not only providing necessary information such as next of kin, but also details of likes/dislikes, preferred activities, chosen form of address, religious affiliation etc. This information needs to be accessible for all members working within the community, as a means of getting to know and understanding each individual. Living plans need to be collaborative, where desired outcomes are co-produced with the person and their family. This means that there is emphasis on the person and their goals, rather than simple delivery of care/support, offering people a voice as to how they want to live their life. Throughout this process and continually, it is important to build on what people can do rather than trying to 'fix' what they cannot do. In this way, positive and encouraging language must be used; there is no place for negative or demeaning language. This makes for a subtle change in the way people see themselves and everyone else within the community. It is important to recognise people's qualities and build on their existing capabilities, creating ownership and recognising the need to work together – the essence of active coexistence. Living plans should also exercise individual's rights to develop external relationships with the wider community, for example Church, Tea Dance, and College.

Doll therapy: The use of dolls ought to be seen as a way of providing some people with a role and purpose. As such, they can be seen as a tool to unlock emotions and enhance communication between two people or the doll and the individual. As dolls are real to some people, it is important that they are treated with respect, i.e. leave a doll in a pram or highchair rather than on the floor or in a box, where members working within the community carry/look after them appropriately. A selection of dolls (various ages, sex, racial skin colour) need to be made available throughout the home - by doing this, you are providing people with an opportunity to actively find a doll if a connection is made. Dolls therefore need to be in good condition and dressed at all times, where prams, highchairs, clothing, bathing facilities and activities such as washing clothes, going for a walk are

available. For this to work, it is crucial that friends and family understand why doll therapy is used and understand the benefits for some people.

Pets (cats, dogs, rabbits) are also a good way of providing role and purpose, as people living and working within the community have shared involvement and responsibility. Having a community pet creates meaningful and purposeful activities, such as cleaning the rabbit's cage or walking the dog.

Activities to take place throughout the day: Each person working within the community is free to facilitate activities. This is better than having an "activity co-ordinator" as this creates formality and does not allow for spontaneity.

Spontaneity is good and helps create a relaxed atmosphere where there is no sense of routine. Spontaneous activities can be facilitated by people working within the community as they can wear "activity belts". These can be created for a small cost and involve purchasing a belt which has lots of pockets, such as a "carpenter's belt" or "DIY belt". Hand cream, feathers, chocolates, dusters etc can then be placed in the numerous pockets and are easily available for natural and unplanned activities to take place.

Use of transport: People should be given the opportunity and are free to partake in activities within the wider community.

Workshops (this could be a large garden shed) are a good way of creating another space for a diverse range of activities to take place, such as ceramics, painting, carpentry, re-building engines, bikes, spray painting cars.

Tailor-made experiences ought to be offered in order to suit individual choices and the re-creation of activities centred on past jobs/hobbies is integral to the running of a community which is actively coexisting.

Active Coexistence within the Community

Communities are enriched by the inclusion and participation of people actively coexisting. These communities are the most important way of providing friendship, support and a meaningful life.

Life story work is one of the most important factors as it not only provides us with a detailed understanding of the individual, but also holds answers to the way in which their dementia may or may not present. This involves asking families to provide a family tree/ family history/list of important events, together with photographs, all of which will be compiled in a scrap book. As a therapeutic activity, this process is best carried out with each person and their family, where people working within the community are available to help. The importance of this book means that people can get to truly know the person. It acts as a means of facilitating dialogue, making connections and providing comfort.

Memory boxes: These are boxes which contain significant personal possessions for each individual. These boxes ought to be kept in people's rooms and aid therapeutic dialogue as it is beneficial for people to sit together and look through/talk about the items.

Recruitment: It is appropriate for people who live in the community to carry out an informal interview and decide if they would like the person to work within the community.

Making connections: It is important to understand and accept the uniqueness of each individual living within the community. For this reason, making connections and the way you do this will differ from one person to the next. It is useful to change and adapt your approach depending upon the individual, i.e. gentle/soft or a more formal tone of voice.

The language of dementia – the meaning behind the words. (i) Look at the person and their life history, do not apply reason and logic, (ii) look for non-verbal signs/cues, i.e. facial gestures, body language, a need for physical contact (hugs, touch, comfort), (iii) always maintain eye contact, sit next to people rather than standing over them, (iv) intense/active listening – believe that everything has a meaning, do not always take words literally, i.e. a person describing themselves as cold could mean hot or even that they feel unsafe, (v) use short, simple sentences, (vi) mirror/copy a person's body language, facial expression (if they are upset, show concern and if they are happy, smile with them), (vii) be aware of the surroundings, e.g. noise may cause agitation, (viii) appreciate that the way someone behaves is an indication of their feelings and emotions.

Identity and the identity of others: Fostering reciprocal relationships and eroding boundaries generally empowers people and creates a collaborative sense of community. It is therefore important and deeply significant to get to know the other members of the community. This takes time and can be achieved by learning about people's history, viewpoints, outlook on life.

People's rights: Ensure that each individual has the right to an independent advocate and the right to be represented.

The optimum ratios of people working and living together are 1:3 or 1:4.

In order to maintain a peaceful atmosphere, a staggered work system ought to be implemented. This involves breaking down the time each person begins work as a means of slowly phasing in and phasing out changes, for example people begin work at 30-minute intervals.

People working within the community do not talk about those living within the community in open spaces (e.g. lounges) or in front of other community members. All personal and sensitive information needs to be discussed in private.

Respectful language needs to be used at all times; this includes all meetings and private conversations. Labelling, institutional or degrading language such as 'aggressive' or

'wanderer' is not acceptable.

Community meetings: This is where the entire community can come together on a weekly basis to discuss matters such as menu changes, re-decoration, and new activities.

Community Facilitators: Each individual living within the community has a chosen community facilitator. This is based upon shared interests and personality matches. The community facilitator is responsible for creating special relationships with a specific number of people who live within the community. This involves knowing each individual and their personalities, as well as recognising their strengths and existing abilities.

Friendships throughout the community: A crucial stage of this process is allowing and encouraging people to make their own friendships, not forcing people to form relationships on a superficial level.

Active coexistence means creating inclusion *and* allowing people the right to be themselves. It is apparent that these two notions may come into conflict with one another. An active community ought to be aware that people may not find meaningful friendships. In this sense, it is important to ensure that each person's emotional and spiritual needs can be met, where similar interests can be shared with others in the community. It is beneficial to "match" people's personalities to make sure that an optimum level of well-being and holism can be achieved.

Upon joining the community, an initial 28-day trial is appropriate as a means of assessing each person's spiritual, emotional and physical well-being. Introductory visits are also a good way of helping people choose the right community for them.

Self-Assessment: Looking for Signs of Active Coexistence

It is important to recognise that active coexistence is dynamic and always in a state of flux. With this comes the recognition that the community will go through good and bad times. This is not only a realistic assumption, but one that acknowledges that perfection is not always achievable on a day-to-day basis. This concept moves away from idealistic ways of evaluation and identifies that the results of the self-assessment will differ from one day to the next. For best results, it is therefore advisable that this process is carried out regularly to give an indication of the community's progression and ensure that the community is actively coexisting.

Community Structure		
	Yes	No
Everyone working in the community has committed to active coexistence by signing a declaration of support which outlines the core ideas and is kept in their personal file.		
Community Leaders are facilitating the community's philosophy "on the floor" on a daily basis.		
Everyone feels that they are of equal value.		
Everyone has a voice and is heard.		
People are aware of each other's feelings.		
People working within the community share responsibility for others and for their actions.		
People are no longer seen as OR called carers/support workers, but community facilitators.		
Everyone in the community feels that they can be themselves.		
Important partnerships between individuals and their families, as well as external agencies are created and maintained.		

Creating An Active Community		
	Yes	No
No barriers: No uniforms; no separate toilets; no separate cups; no separate mealtimes; no 'staff' rooms; no locked doors; freedom to access all living areas and gardens at all times; freedom to use the resources of the home (e.g. kitchen).		
Positive risk assessments are carried out instead of negative risk assessments.		
No institutional activities or regimes.		
People are involved in the daily running of their community.		
People are provided with opportunities for fulfilment throughout the day.		
People face challenges together and respond to people's emotions.		
People are supported with their personal challenges and a solution is sought.		
Discouraged use of antipsychotics.		

The community is constantly reviewed as a means of achieving improvement.		
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The Colour of the Community		
	Yes	No
The environment is domestic, age-appropriate and homely. The living spaces are small and seat a maximum of 14 people.		
Separate communities for (i) older people living with Dementia; (ii) younger people living with Dementia and (iii) people living with Alcohol-Related Dementia.		
Comfortable seating with a mixture of sofas and chairs.		
Background music can be heard and has been chosen by the people living in the community.		
Limited use of televisions.		
Living spaces are full of clutter.		
Rummage boxes surround the living spaces and are freely available for use.		
Walls are decorated with sensory boards.		
Corridors are colourful and have interactive prompts and decoration.		
Each person has a personalised room with their name displayed clearly on the door.		
Bathrooms are not clinical but warm and interesting.		
Illustrative signs/prompts guide people to different living spaces.		
No locked doors: Everywhere (even the garden) is accessible at all times.		
Garden and outside areas are used. They are accessible and practical, with good seating areas.		
Busy and relaxed areas are available for people to enjoy.		
No visiting hours for friends and family. Friends and family are allowed to partake in mealtimes and the running of the home.		
Limited use of mirrors.		

Community Life		
	Yes	No
People feel free to express emotion.		
Daily life is made up of very little or no routine.		
People living within the community come first, tasks come last.		
All members of the community are involved in the daily running of the home.		
Mealtimes are a social occasion where all members of the community eat together. People choose their courses from a menu. Menus are changed each week. Menus are created by people living and working in the community.		
Food is available 24 hours-a-day.		
People freely express their likes and dislikes.		
Living plans are no longer called care plans. They are extremely detailed and are accessible for all members working within the community. They are collaborative and created by the person and their family. There is emphasis on the person and their goals and only positive language is used.		

Dolls are treated with respect. A selection of dolls (various ages, sex, and racial skin colour) are available. Friends and family understand the benefits of doll therapy for some people.		
There is a community pet which everyone is involved with and responsible for.		
Activities take place throughout the day. There are no “activity co-ordinators”, instead everyone is free to facilitate activities.		
Activities are not limited to the home. People are provided with opportunities to partake in activities within the wider community.		
Spontaneous activities take place. People working within the community wear “activity belts”.		
Workshops are available for a diverse range of activities to take place.		
Tailor-made experiences are offered to suit individual choices. Activities centred on past jobs/hobbies take place.		

Active Coexistence within the Community		
	Yes	No
Life story work takes place. Each person has their own personalised scrap book which is full of photos and details of their family history.		
Each person has a memory box which is kept in their room.		
People who live in the community carry out informal interviews and decide if they would like prospective members to work within the community.		
People working within the community change/adapt their approach depending upon the individual they are trying to make a connection with.		
People working within the community understand the language of dementia – the meaning behind the words.		
People know and understand other members of the community.		
Each person has the right to an independent advocate.		
The ratio of people working and living together is 1:3 or 1:4.		
A staggered work system is in place.		
People working within the community do not talk about those living within the community in open spaces or in front of other community members.		
Respectful language is used at all times.		
Community meetings take place on a weekly basis.		
Each individual living within the community has a chosen community facilitator. All community facilitators are clear about their responsibilities.		
People are allowed and encouraged to make their own friendships.		
Each person’s emotional and spiritual needs are being met, where similar interests are shared with others in the community.		
Introductory visits and 28-day trials are used.		