# Findhorn Ecovillage and Community

# NEEDS ASSESSMENT FOR A CARING COMMUNITY COORDINATOR

WITH SPECIAL FOCUS ON DEMENTIA

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Written by Ilona Kästner
Commissioned by: Caring Community Circle, Findhorn, Scotland

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# **Executive Summary**

The Findhorn Community and Ecovillage is an aging community with a higher average age than the rest of Scotland. The largest age group in the community, the 55-64 old, represent about 30% of the whole community. Within the next two decades, this age group will be 75 and older. The community has to prepare for a rapid increase of people in the need of care, including those living with dementia, as well as an increasing number of family members and friends looking after them.

The Caring Community Circle, an informal community embedded volunteer group that has facilitated a caring community culture and social support infrastructure for vulnerable community members since 1996 is reaching its natural limits due to health issues and age. The natural support network within the community based on personal relationships is stretched and not sufficient to meet the rising demand for support within a continuously growing and diversifying community.

A new social infrastructure is required to fill the growing gap to respond to the future challenges of an aging community and to complement the national social health and care services in an efficient way.

The recommendation is to create the position of a Caring Community Coordinator with special focus on dementia. A person in this role can support and enhance the resilience of the community, the people in need of care as well as their families and friends.

Enabling people to stay in their homes to experience a decent life quality and independent life as long as possible, as well as integrating the complex condition of dementia from the early phase of pre diagnosis to more severe states of the illness, will have a beneficial impact on the overstressed national health and social care services.

# **Key Findings**

- The Findhorn Community and Ecovillage is an aging community with a higher concentration of baby boomers<sup>1</sup> than the rest of Scotland, about 30%, compared to 16.6% in Scotland, are now 55-64 and will reach the age of 75 and over between now and 2041.
- Since 1989, at least 69 community members have been in the need of care. In 2017, around 48 people in the community received care, 28 of which were of 75 years old or older.<sup>2</sup>
- In 2019 the Caring Community Circle is aware of 10 people within the Findhorn Community suffering from dementia or significant memory problems. 9 of which are aged over 65.

<sup>&</sup>lt;sup>1</sup> Britain experienced a relatively high population growth during the 1960s, which can be seen today in the larger number of people in their mid-50s to mid-60s. source:

https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/overviewoftheukpopulation/mar2017/previous/v1

<sup>&</sup>lt;sup>2</sup> The numbers listed here do not represent the factual numbers but as recalled by present Caring Community Circle volunteers.

- In 2019, about 129 people provide support and care for the vulnerable members within the community, of which 95 (74%) are informal carers like volunteering community members, family and friends.
- 2 of the members of the Caring Community Circle **died** within the last 18 months, **several others** are **over 70** and others are limited through health issues.

## Introduction

People in Scotland are living much longer due to the improvements in living standards, social services and health care. The fastest growing age group in Scotland is projected to be those aged 75 and over, increasing by 79% from 2016 to 2041.<sup>3</sup> For many people these extra years of life mean that they are living with multiple conditions, complex needs and illnesses, dementia being one of them.

This is posing an increasing health challenge for individuals, families and communities. In 2017 an estimated 93.282 people lived in Scotland with dementia, only around 3.200 of these people were under the age of 65. New research has shown that people develop dementia much later than expected when they are already in complex care need. By 2020 it is likely that there will be 20.000 new cases diagnosed each year<sup>4</sup>; and it is estimated that only 50% of people living with dementia currently receive a formal diagnosis.<sup>5</sup>

This increasing demand leaves the national social care and health system at a crisis point. Research undertaken by Age Scotland in 2018 found that "too many older people in Scotland are waiting for too long to access the social care they need."

Scotland's National Dementia Strategy for 2017-2020 is ambitious and aims to deliver "high quality, person centred support for people with dementia, their families and carers from the point of diagnosis to the end of life", yet the gap between policy and real life experience remains wide.

The Findhorn Community and Ecovillage has established over the last 20 years a caring, dementia friendly community culture and infrastructure based on volunteers that provide support to its members thereby enabling a decent quality of life, independence, and wellbeing as long as possible. Within the

<sup>&</sup>lt;sup>3</sup> National Records of Scotland, August 2018 <a href="https://www.nrscotland.gov.uk/files/statistics/nrs-visual/rgar-2017-infographic-booklet.pdf">https://www.nrscotland.gov.uk/files/statistics/nrs-visual/rgar-2017-infographic-booklet.pdf</a>

<sup>4 &</sup>lt;u>www.gov.scot/publications/scotlands-national-dementia-strategy-2017-2020</u> page 5

<sup>&</sup>lt;sup>5</sup> According to the experienced Dementia Advisor for Moray, Wendy Menzies, Alzheimer Scotland, www.alzscot.org

<sup>6 &</sup>quot;In 2018 43 % of older people assessed as having critical or substantial needs did not receive the services they required within the six week period outlined in the National Eligibility Criteria" <a href="https://www.ageuk.org.uk/globalassets/age-scotland/documents/policy-and-engagement/age\_scotland\_waiting\_for\_care\_report\_may\_2019.pdf">https://www.ageuk.org.uk/globalassets/age-scotland/documents/policy-and-engagement/age\_scotland\_waiting\_for\_care\_report\_may\_2019.pdf</a>, page 3.

Service pressures such as increased demand and limited resources are named as causes for the delays

<sup>&</sup>lt;sup>7</sup> https://www.alzscot.org/campaigning/national\_dementia\_strategy

next two decades the community faces significant demographic changes and an increasing prevalence of dementia. The existing Caring Community Circle that was established to complement the national public social care and health services is not in a position to face this challenge.

A new response is required to maintain and continuously develop a resilient community environment, culture, social infrastructure and awareness that can work together with the public services to enable and enhance efficient, integrated, and coordinated community support.

# The Findhorn Community & Ecovillage

The Findhorn Community was formed in 1962 and has grown and evolved into a diverse, open spiritual community and ecovillage with different levels of community involvement. It is based in Moray, northeast Scotland, a rural area with a history of low wages and known for difficult recruitment into NHS and local authorities.

In 1998 the New Findhorn Association (NFA) was set up as an unincorporated membership association to serve as an umbrella for individuals and organisations within a radius of 50 miles of the Findhorn Community. Members agree to live and work by a set of core values laid out by the community and linked to the global ecovillage model of ecological, economical, cultural and spiritual sustainability.

The largest and oldest organisation within the NFA is the Findhorn Foundation (FF), a charitable community based adult learning centre at the heart of the spiritual community.

# **Demographics**

# **Age Groups**

An estimated 600 people are currently either an individual member of the NFA, a co-worker of the FF or are going through a long-term residential training programme (LEAP)<sup>8</sup> run by the FF<sup>9</sup>. In addition, about 37 business memberships, charitable and community association memberships are listed on the NFA community map.<sup>10</sup>

<sup>&</sup>lt;sup>8</sup> Learning Education Apprenticeship Programme

<sup>&</sup>lt;sup>9</sup> The current NFA Community Telephone Directory (including co-workers of the Findhorn Foundation) lists 575 individual members, last updated on January 2019. The FF employs 134 co-workers and 9 minors in June 2019 including LEAP students (source: Jürgen Muthmann, business analyst, Findhorn Foundation). Not all FF co-workers are listed in the phone directory.

<sup>&</sup>lt;sup>10</sup> https://kumu.io/embed/f5d7241e9d0dc2b69564f4e0d139c404#organisational-map-of-the-findhorn-ecovillage-community. The map was created and last updated in 2016.

Within the Findhorn Community (NFA and FF) the biggest group of people are aged 55-64 and represent an estimated 30% of the whole community. In Scotland as a whole this age group represents about 13.3% of the population (mid-2018). Within the next 10-20 years this age group will become 75 and older.

For Scotland as a whole the age group 75 and older is projected to increase by 79% over a 25-year period, between 2016 and 2041.<sup>13</sup>

As of 2016, around 30.1% in the NFA and 22.4% in the FF are aged 65 and older. This is again a higher rate compared to Scotland as a whole with an estimated 19% of the population aged 65 and older, projected to rise to 25% by 2041. The population of all other groups in Scotland, below 65, are projected to decline over the same time period. 15

All people aged 55 and over represent in total an estimated 60% in the NFA and 54.5% in the FF, compared to 32.2% in Scotland.<sup>16</sup>

The Findhorn Community and Ecovillage is an aging community with a higher concentration of baby boomers than the rest of Scotland reaching an age of 75 and over between now and 2041.

Table 1: Estimated population NFA by age in 2016<sup>17</sup>

Age Range	Respondents	%
18 - 24	3	0.9
25 - 34	12	3.6
35 - 44	44	13.2
45 - 54	74	22.2
55 - 64	100	30
65 - 74	86	25.8
75 +	14	4,3
Total	333	100

<sup>&</sup>lt;sup>11</sup> According to a survey that was undertaken by the NFA in 2016. The survey had 339 respondents of which only 15 (4,5%) where FF co-workers. Although the Findhorn Foundation is a member of the NFA as an organisation, most co-workers of the FF are not individual members of the NFA. Although this is weak data, it can still show a tendency.

<sup>&</sup>lt;sup>12</sup> https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-estimates/mid-year-population-estimates/mid-2018, Table 1: Estimated population by age and sex, Scotland, mid-2018

<sup>13</sup> https://www.nrscotland.gov.uk/files//statistics/rgar/2017/rgar17-corrected-08-04-19.pdf p.11

<sup>&</sup>lt;sup>14</sup> NFA survey (2016); FF accounts

<sup>15</sup> https://www.nrscotland.gov.uk/files//statistics/rgar/2017/rgar17-corrected-08-04-19.pdf p.11

<sup>16</sup> https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-

theme/population/population-estimates/mid-year-population-estimates/mid-2018, Table 1: Estimated population by age and sex, Scotland, mid-2018

<sup>&</sup>lt;sup>17</sup> An online survey undertaken by the NFA in 2016 had 339 respondents of which only 15 (4,5%) where FF co-workers. Although the Findhorn Foundation is a member of the NFA as an organisation, most co-workers of the FF are not individual members of the NFA.

Table 2: Co-workers Findhorn Foundation by age in 2019<sup>18</sup>

Age Range	Co-workers	%
18 - 24	2	1.5
25 - 34	8	6
35 - 44	22	16.4
45 - 54	29	21.7
55 - 64	43	32
65 - 74	26	19.4
75 +	4	3
Total	134	100

Table 3: Comparison NFA and FF by age<sup>19</sup>

Age Range	% NFA 2016	% FF 2019
18 - 24	0.9	1.5
25 - 34	3.6	6
35 - 44	13.2	16.4
45 - 54	22.2	21.7
55 - 64	30	32
65 - 74	25.8	19.4
75 +	4.3	3

# **Vulnerable Groups**

Since 1989 at least 69 community members have been in the need of care due to chronic illness, cancer, mental health, learning disabilities, because they reached their end of life or they lost a loved one.

In 2018, 48 people in the community received care, 5 of which required only temporary care and 28 of which were aged 75 or older.<sup>20</sup>

This represents about 8% of the estimated 600 Findhorn community members, and 4.7% were in need for care and aged 75 or older.

Together, the age groups 55-64 and 65-74 make up just over 50% of all current community members. With these two groups moving into the age group 75 and older within the next 22 years, the demand for formal and informal care, including end of life care, will increase rapidly.

<sup>&</sup>lt;sup>18</sup> Data from FF accounts, Jürgen Muthman, 2019

<sup>&</sup>lt;sup>19</sup> Data from NFA survey 2016 and FF accounts 2019

<sup>&</sup>lt;sup>20</sup> All numbers are anecdotal, as recalled by present Caring Community Circle volunteers

Table 4: Care in Findhorn Community (NFA, FF), conditions, 1989 to date (anecdotal)<sup>21</sup>

Condition	People
End of life, no cancer	23
End of life, with cancer	14
Chronic severe illness	4
Mental health	9
Learning disabilities	6
Sudden death, support for	
family	13
Total	69

Table 5: Care in Findhorn Community (NFA, FF), age groups, 2018 (as reported by Caring Community Circle volunteers)<sup>22</sup>

Group	People
Elderly (75+)	28
Adult	12
Youth	8
Total	48
Of which:	
Temporary	5
Died (2 aged 75+, 1 adult)	3

### Carers

A strong informal support network based on personal relationships has been built up within the Findhorn Community over many years.

In 2018, about 129 people provided support and care for vulnerable community members, of which 95 (74%) were volunteering community members, family and friends, and 28 (22%) were paid personal assistants.

These informal carers and especially family members who are caring for a partner or relative often experience significant restrictions in their social lives and health due to this complex and demanding task.

More sustainable interventions are needed to also support the people who are standing behind the people in need of care so they can cope with and manage the diverse and often long-term stresses imposed on them better.

<sup>&</sup>lt;sup>21</sup> Source: Caring Community Circle, June 2019, Cornelia Featherstone

<sup>&</sup>lt;sup>22</sup> Source: Caring Community Circle, June 2019, Cornelia Featherstone

In addition, the naturally grown support network within the community reaches its limit as it faces the enormous growth in numbers of people in need of care within the next two decades. For two reasons: The long-term community members who have been part of building the community for many years and are the key agents within this informal support network are now becoming the people who need the care.

At the same time, the community has grown and diversified. People live much further apart and are spread over a wider region compared with 30 years ago. The existing community networks are smaller, more specific, but less integrated and do not span across all categories of the community anymore as they did in the past.

Table 6: Carers in Findhorn Community 2018 (as recorded by Caring Community Circle volunteers)<sup>23</sup>

Group	Carers
Community volunteers	32
Family	37
Friends	26
Paid carers	28
Of which temporary carers	6
Total	123

### **Dementia**

In 2019 the Findhorn Community includes 6 people suffering from dementia with other complex needs, and at least 4 people who have significant memory problems. 9 of these 10 people affected by dementia are aged over 65, 1 person is between 60-65. Since 1989 the collective memory of the CCC refers to 13 cases of dementia.<sup>24</sup>

An estimated 90,000 people have dementia in Scotland (statistics for 2017). Only around 3.5% (3,200) of these people are under the age of 65. In Moray there are an estimated 1.820 people living currently with dementia.<sup>25</sup>

In 2020 an estimated 19,473 people will be newly diagnosed with dementia, which is an increase of 17% since 2014. Of this number only about 648 will be under 65 and about 15.793 will be 75 and older. The age group estimated to have the most diagnosis of dementia seems to be the 80-84 olds.<sup>26</sup>

<sup>&</sup>lt;sup>23</sup> Source: Caring Community Circle, June 2018, Cornelia Featherstone

<sup>&</sup>lt;sup>24</sup> Source: Caring Community Circle, June 2019, Cornelia Featherstone

<sup>&</sup>lt;sup>25</sup> https://www.alzscot.org/campaigning/statistics

<sup>&</sup>lt;sup>26</sup> https://www.gov.scot/publications/estimated-projected-diagnosis-rates-dementia-scotland-2014-2020/pages/2/

Due to the rapid demographic changes within the Findhorn Community the prevalence of dementia is likely to increase at a higher rate than in the rest of Scotland.

As well as more people being diagnosed with dementia in their later life there will be also more families and friends affected. The social costs of caring for a person with dementia is likely to have an impact on the individuals and on the community.

Table 7: Known dementia in Findhorn Community, 2019<sup>27</sup>

Condition	people
significant memory problems	4
late stage dementia	6

# The Caring Community Circle (CCC)

# History to date

In 1996 a small group of NFA members who were former health care professionals founded the Community Care Circle (CCC) to enable the provision of care for the times when people are in need, through, for instance, mental health problems, learning difficulties, cancer, age, the final stages of life and dementia. The CCC is still run as a volunteering circle within the NFA.

Since its founding, the CCC has held an awareness of vulnerable people in the community and has facilitated different aspects of care, like accommodation, care workers, funding, social inclusion, and links with social work and health care services. The group also provided information and education on skills and resources relevant for the stage of dependence through a series of workshops, "The Curriculum for the 4th Age".<sup>28</sup>

The CCC and its activities are embedded in and supported by a rich network of Findhorn Community institutions and members. They provide not only personal and professional services in holistic health care<sup>29</sup> and interfaith ministry but also social inclusion activities on a regular basis such as Yoga, Fitness Classes, Qigong, Taize singing, community meditations, painting, pottery, 5 Rhythms Dance, etc.

<sup>&</sup>lt;sup>27</sup> Source: Caring Community Circle June 2019

<sup>&</sup>lt;sup>28</sup> https://findhorn.cc/groups/community-care-circle

<sup>&</sup>lt;sup>29</sup> The Findhorn Community has a Code of Ethics based practitioners directory and is associated with a professional multidisciplinary health centre, HealthWorks, in Forres,

In 2018 the name was changed from Community Care Circle to Caring Community Circle, responding to the shift in the national health strategy from institutionalised care to social services providing community care.

The Caring Community Circle is now holding the vision of co-creating an exemplary caring community culture from cradle to grave. It aims to maintain and develop a community culture, infrastructure and environment within the wider Findhorn Community that is preventative, supports care in community, enables people to live independently in their homes as well and as long as possible, and eases an efficient access to National Health and Social Care.

### **Achievements**

Since its foundation in 1996 the CCC has facilitated and supported an informal network to enable resilient community care for over 69 vulnerable community members, including the support for family members and close friends. Several Buddy Groups for peer-support were encouraged. The group has developed and implemented a "Curriculum for the 4th Age" to raise awareness and educate people on the phase of dependence in later life. This included a series of 15 workshops on diverse subjects such as financing care, facing fears around aging and death, making a will, power of attorney, dementia or funeral preparations.

A fitness class was created in 2014, which now runs independently on a weekly basis. Over the period around 48 community members have engaged with it, most of them aged over 55.

The group was also involved in the development of affordable housing units to enable older community members to live a more socially inclusive life in their more dependent years.

More recent achievements include:

- A workshop series on Dementia (2019)
- A Christmas dinner organised for the volunteer/family carers by a designated Carers Support volunteer (2018)
- A lift-match scheme for people in need, set up in collaboration with Moray Carshare (in operation since 2019)
- The setting-up of a cross-organizational Mental Health Strategy Group and a Health & Wellbeing in Community Training Programme (2019)

# **Structural Challenges**

The CCC in its current form faces two major structural challenges.

Firstly, its existing members are aging and their professional background and skills are not replicable. Most of the people involved are former health care professionals and are currently not replaceable from within the community on

a volunteer basis. This leaves a gap in knowledge and expertise since the circle of the original founders is now strongly limited in its capacity due to age and health issues.<sup>30</sup>

Secondly, the existing CCC is based on and has evolved from social networks within the community. A volunteer circle can not respond adequately to the projected rising demand that is approaching the community within the coming years. This demand will increase significantly within the next two decades due to a rapidly aging community and the related health challenge of dementia. The attempt to create satellite people care circles in different sub communities and neighbourhoods was largely unsuccessful. The required support network has to go beyond personal relationships to be more resilient and sustainable.

### Conclusions

In order to respond to the major challenges of an aging community, including the increase of dementia, the existing Caring Community Circle has to evolve from an informal volunteer group and network to a more sustainable structure.

A first step was realised in August 2018. The CCC became a sub division of the community charity Park Ecovillage Trust (PET)<sup>31</sup> and as such has obtained a company structure and charitable status.

To further develop a preventative, caring and dementia friendly community culture and an effective safety netting for vulnerable community members and those caring for them, a paid Caring Community Coordinator position will be required.

# **Recommendations**

### **Caring Community Coordinator**

- To maintain and develop the existing caring community culture, social infrastructure, capacities and other resources within the Findhorn Community a paid position within the CCC is recommended.
- Through this central position the experiences, skills, connections and other resources of those involved in care within the community and in

<sup>&</sup>lt;sup>30</sup> 2 of the original founders died within the last 18 months, several others are over 70 now and others are limited through health issues.

<sup>31</sup> https://parkecovillagetrust.co.uk/caring-community-circle/

Moray can be harnessed. Thus making these resources accessible to those in need in a more efficient and sustainable manner.

- This position should be designed to build inclusive support for the people in need of care and for those caring for them. It will enable more diverse care teams and enhance resilience and social integration.
- As part of the wider role of the Caring Community Coordinator a special focus on dementia is recommended to prepare for and meet the projected increase in numbers of this complex disease within the community.
- A paid position with special focus on dementia will ensure an integrated support in all stages of the disease and make sure all available resources are used efficiently. The post can serve as a link between the community and national social health and care services. It will help to facilitate a better implementation of the community support aspects of the 5 and 8-Pillar Model as identified by the National Dementia Strategy 2017-2020 for post diagnosis support and people living at home during moderate and severe stages of the illness.<sup>32</sup>

<sup>32</sup> https://www.alzscot.org/campaigning/national\_dementia\_strategy