

A manual for the
creation and evaluation
of Compassionate
Communities

Essential benefits of Compassionate Communities

**This manual, Essential benefits of
Compassionate Communities, was developed
in collaboration with experts from around
the world and led by researchers from three
Compassionate Communities:**

**Bern (Switzerland), Buenos Aires (Argentina),
and Medellin (Colombia).**

Project Leadership

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Context

Rooted in the understanding that care for the ill, dying, and bereaved should extend beyond the confines of healthcare systems, this movement emphasizes the role of the entire community in supporting one another during life's most challenging moments

Compassionate Communities represent a transformative approach to care that acknowledges the deep interconnection between individual well-being and the collective strength of society. Rooted in the understanding that care for the ill, dying, and bereaved should extend beyond the confines of healthcare systems, this movement emphasizes the role of the entire community in supporting one another during life's most challenging moments. As envisioned by Professor Allan Kellehear in the Compassionate City Charter, these communities recognize that the natural cycles of sickness and health, birth and death, love and loss are not just personal experiences but societal ones, demanding a collective, empathetic response.

Kellehear's Charter outlines a comprehensive framework for cities to foster compassion through specific, actionable steps. It calls on schools, workplaces, religious institutions, and local governments to adopt policies and initiatives that normalize conversations about death, provide support for caregivers, and encourage public engagement with issues related to aging, dying, loss, and care. This model of a Compassionate City is built on the premise that care is a shared responsibility that extends into every facet of community life.

Since Kellehear's call on Compassionate Communities, many of them have developed all over the world, responding to the needs, characteristics and resources of each community. As a result, Compassionate Communities have developed and implemented actions differently. Some frameworks have been proposed for evaluation of Compassionate Communities such as the Canadian Compassionate Communities Evaluation Guide*. However, so far, there are no agreed-upon benefits or outcomes against which cities that are already developing a Compassionate Community can measure their achievements and identify potential gaps. With the intent to bridge this gap, we conducted a research project to identify the core benefits of Compassionate Communities, retrieving potential benefits from scientific publications and focus groups with members of three Compassionate Communities and other type experts.

* <https://www.bc-cpc.ca/compassionate-communities-evaluation-guide/>

This manual aims to bridge the foundational Charter with practical guidance for both evaluating and developing Compassionate Communities. The 18 key benefits identified by our research form the core of this guide, offering a comprehensive list of outcomes to be assessed in already existing programs or to inspire and guide the creation of new initiatives. These benefits, which range from empowering citizens and training the community to fostering research and improving patient care, encapsulate the multifaceted impact of Compassionate Communities.

This is a starting point for further development of other specific outcomes. In view of the different culture, organization and structure of communities, education and healthcare, there can be no universally valid, internationally standardized set of outcomes. That would not be the goal. In fact, this research project has shown that probably only half of the achievable benefits are actually generalizable and internationally comparable. The second half should then be defined and evaluated locally or regionally. A combined global and local approach might be the way to go.

By aligning this manual with the Compassionate City Charter, we aim to provide a tool that not only guides the development or evaluation of Compassionate Communities but also serves as a catalyst for the global movement towards a more caring and connected society. Our collective goal is to ensure that every person, regardless of their circumstances, can live in a community that recognizes, respects, and responds to the profound experiences of illness, caregiving, loss, and death with compassion and dignity.

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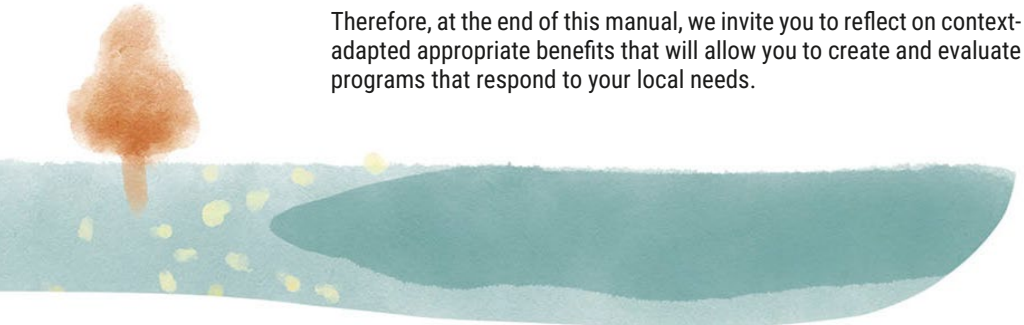
Why we developed this manual

We want to engage the community in the creation, participation, and assessment of Compassionate Communities. Cities that have been supporting or establishing one and want to evaluate its benefits, will have this manual as a resource to do so.

Why to use this manual

The benefits presented in this manual were identified and selected through a collective process involving multiple stakeholders involved in widely diverse compassionate communities from several countries. Hence, they are intended to assist compassionate communities from all over the world in different stages of development. Stakeholders may evaluate their own compassionate communities by using the core benefits described in this manual. They may then create additional outcomes adapted to needs within their specific context. Such approach will be also helpful to understand the different benefits and priorities of different compassionate communities.

Therefore, at the end of this manual, we invite you to reflect on context-adapted appropriate benefits that will allow you to create and evaluate programs that respond to your local needs.



Why to use this manual



Guide the creation of new Compassionate Communities:

The list of essential benefits can be used as a guide for planning actions within your community.

or



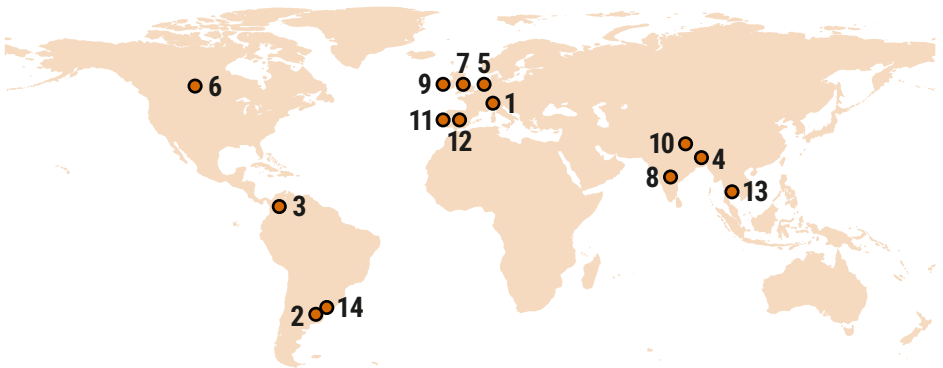
Evaluate already existing Compassionate Communities:

The list can be used to identify areas for improvement, to inform political decisions and resource allocation, or for research

**Use these specific benefits
in conjunction with already
existing guides for developing
Compassionate Communities
or evaluation frameworks**

Development of the manual: previous steps

The work carried out to identify the essential benefits of compassionate communities was conducted as part of an international collaboration led by the Compassionate Communities of three cities in three different countries: **1**endlich.menschlich. (Bern, Switzerland), **2**Buenos Aires Todos con Vos (Buenos Aires, Argentina), and **3**Red Compasiva (Medellín, Colombia). In addition, it included experts who participated in the development of other programs in countries such as **4**Bangladesh, **5**Belgium, **6**Canada, **7**England, **8**India, **9**Ireland, **10**Nepal, **11**Portugal, **12**Spain, **13**Thailand, and **14**Uruguay.



Step 1

Initially, we conducted fieldwork in the three leading cities to collect information to identify benefits from the point of view of different experts, including the general community, health care providers, members of (non-) governmental organizations allied with the Compassionate Communities, and the coordinators of each program.

Step 2

Then, we reviewed the literature to identify benefits reported in scientific publications.

Step 3

We made a list of all the benefits identified and conducted two rounds of a Delphi survey in which, in addition to the participants from previous phases, other experts were invited from the countries mentioned above.

Step 4

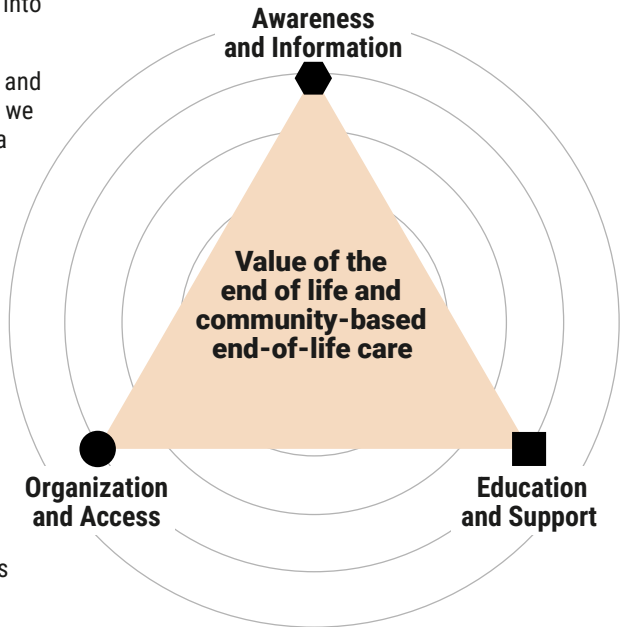
Finally, we had a consensus meeting to define the final list of essential benefits of Compassionate Communities.

Sustainability triangle of Compassionate Communities

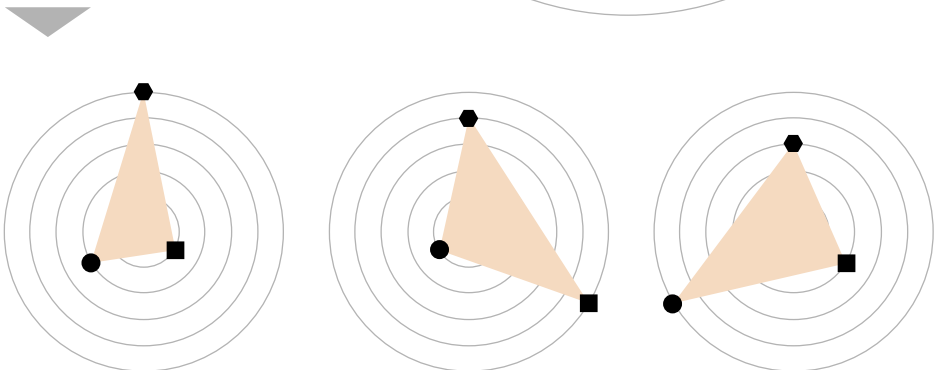
We have grouped the benefits into three categories

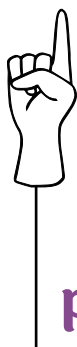
To ensure the smooth running and sustainability of the program, we believe that there must be a balance between the benefits achieved in each category.

A balanced distribution of the achieved benefits across the three categories would look like this:



Instead, unbalanced distributions would look like this:





How to implement this manual to design or develop a Compassionate Community program



For guidance on the steps or considerations in developing a Compassionate Community program, we invite you to consult available toolkits such as:



The Scottish Compassionate Communities Toolkit, which provides practical advice on starting compassionate communities



The mapping guide “Creating Community Care Networks for End of Life Support -HELP Community Asset Mapping Guided” developed by the Healthy End of Life Project (HELP)

Keep in mind when designing the program that these are essential benefits that the Compassionate Community should bring to the community:

◆ Awareness and Information benefits:

1. To empower citizens, including underserved and forgotten populations, to recognize and get what they need.
2. To make the compassionate community visible, including the information and training received, so that it reaches more people.
3. To help people to become more familiar with end of life and death through information, conversations, or experiences.
4. To encourage people to reflect on life and the future, including old age, illness and death, and to become more accepting of them.
5. To change (improve) regional and cultural attitudes, including attitudes towards vulnerability, illness, and death.
6. To recognize the wisdom of the community and ancestral people; learn from it and embrace it.
7. To make visible, characterize, and prioritize the caregivers and their needs while increasing their confidence by both receiving training and feeling supported in caregiving.

● Organization and Access benefits:

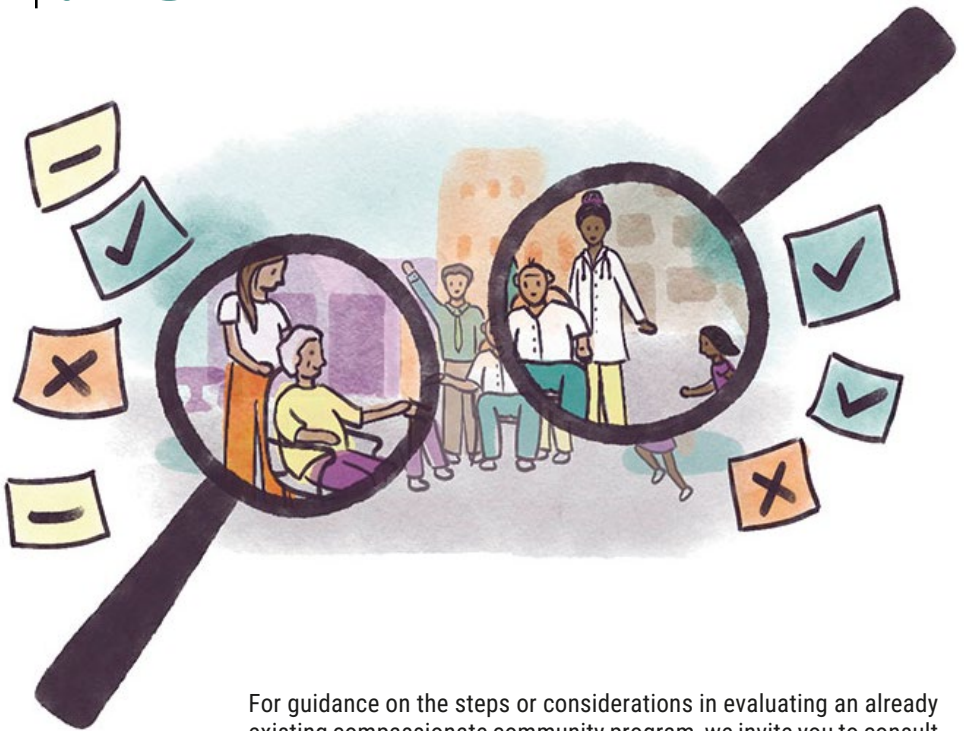
1. To facilitate the creation and coordination of caregiver and community networks, both locally and across cities, and identify/support existing initiatives.
2. To strengthen the institutions belonging to the network and promote alliances between those with similar interests.
3. To identify volunteers (including experienced caregivers) of different ages who have time and resources to support care.
4. To provide access to centralized information about other institutions and what to do in each case to direct people to someone who can solve their need.
5. To integrate different disciplines and sectors of society to achieve collaborative work.

■ Education and Support benefits:

1. To foster research in the field of Compassionate Communities.
2. To promote in the community the awareness that at some point we may have to take care of someone and be prepared for when this happens.
3. To generate spaces (and provide tools) to talk about grief, normalize it, and address it from the community so as not to depend on health professionals.
4. To encourage collective responsibility in society to accompany and support each other, particularly at the end of life.
5. To improve the quality of patient care by getting closer to patients, listening to them, respecting their autonomy, supporting them, and addressing their needs.
6. To train the general community (children and young people, caregivers, patients, and health care professionals) in compassion, caregiving, end of life, death, and bereavement, independent of whether they need these skills at present or may need them in the future.



How to implement this manual to evaluate a Compassionate Community program



For guidance on the steps or considerations in evaluating an already existing compassionate community program, we invite you to consult available toolkits such as:



**The Canadian Compassionate Communities
Evaluation and Implementation framework.**

Checklist of benefits for ‘Awareness and Information’

Benefits or outcomes are not yet scalable indicators such as “more than 50% of the population have actively participated in a one day course ‘how to care for a severely ill family member’ sponsored by the city administration over a period of 5 years”. The idea is to identify and define ways and potential available measures (e.g. administrative data) how to qualify the level of achievement for each of the benefits.

Is the Compassionate Community:

1. Empowering citizens, including underserved and forgotten populations, to recognize and get what they need?

Examples of ways to assess this benefit are:

- i) Identify projects and initiatives of the communities.
- ii) Measure the number of people trained in community empowerment for the enforcement of their rights.

No
 Yes

If yes, please specify:

2. Making the compassionate community visible, including the information and training received, so that it reaches more people?

Examples of ways to assess this benefit are:

- i) Analyze public discourse and media content,
- ii) create databases on e-strategies and outreach, communication and training activities.

No
 Yes

If yes, please specify:

3. Helping people to become more familiar with end of life and death through information, conversations, or experiences?

Examples of ways to assess this benefit are:

- i) conduct surveys before and after participation, assessing knowledge of end-of-life topics*
- ii) Measure participation in events, workshops, or other community experiences related to death, dying, and bereavement.*

No

Yes

If yes, please specify:

4. Encouraging people to reflect on life and the future, including old age, illness and death, and to become more accepting of them?

Examples of ways to assess this benefit are:

- i) to identify perceptions of aging, illness and death before and after participating in Compassionate Communities,*
- ii) to distribute aging and death acceptance questionnaires.*

No

Yes

If yes, please specify:

5. Changing (improving) regional and cultural attitudes, including attitudes towards vulnerability, illness, and death?

Examples of ways to assess this benefit are:

- i) to identify pre- and post-perceptions of vulnerability, illness and death before and after participating in Compassionate Communities,*
- ii) to measure death literacy index*

No

Yes

If yes, please specify:

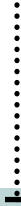
6. Recognizing the wisdom of the community and ancestral people; learning from it and embracing it?

Examples of ways to assess this benefit are:

- i) identifying the practices and resources related ancestral people and seeing to what extent they are included in the social practices of that community in relation to the care of people,*
- ii) reporting of interviews with community leaders of the ancestral population they represent to learn from their modalities of care, and support in chronic illness, end of life and grief.*

No

Yes



If yes, please specify:

7. Making visible, characterize, and prioritize the caregivers and their needs while increasing their confidence by both receiving training and feeling supported in caregiving?

Examples of ways to assess this benefit are:

- i) to report whether publications have been made about the needs of caregivers,*
- ii) to measure the number of group listening activities and testimonies of the caregiving experience*

No

Yes



If yes, please specify:

● Checklist of benefits for “Organization and Access”

Is the Compassionate Community:

1. Facilitating the creation and coordination of caregiver and community networks, both locally and across cities, and identifying/supporting existing initiatives?

Examples of ways to assess this benefit are:

i) to report on measures taken to promote communities at the local level (e.g., neighborhood events)

ii) to report on whether there is a central point of contact or coordination of neighborhood or regional networks.

No
 Yes

If yes, please specify:

2. Strengthening the institutions belonging to the network and promoting alliances between those with similar interests?

Examples of ways to assess this benefit are:

i) to identify the level of formal and informal alliances between institutions

ii) create a sociogram of the institutions

No
 Yes

If yes, please specify:

3. Identifying volunteers (including experienced caregivers) of different ages who have time and resources to support care?

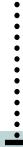
Examples of ways to assess this benefit are:

i) Report the number of volunteers identified in the compassionate community

ii) evaluate whether calls and meetings have been made to identify them and the results of these calls.

No

Yes



If yes, please specify:

4. Providing access to centralized information about other institutions and what to do in each case to direct people to someone who can solve their need?

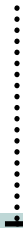
Examples of ways to assess this benefit are:

i) to see if there is an action map on how to act in response to each need

ii) evaluate if there are directories and portfolios of services of the institutions associated with the compassionate community available to be consulted by the general community, for example through websites

No

Yes



If yes, please specify:

5. Integrating different disciplines and sectors of society to achieve collaborative work?

Examples of ways to assess this benefit are:

i) carry out a geographic mapping of key actors and actions,
ii) evaluate the initiatives that have been carried out between various disciplines (joint initiatives)

No

Yes



If yes, please specify:

■ Checklist of benefits for ‘Education and Support’

Is the Compassionate Community:

1. Fostering research in the field of Compassionate Communities?

Examples of ways to assess this benefit are:

- i) evaluate the funding acquired for research projects, the number of projects in progress and the number of articles published;*
- ii) create a database on projects and publications by institutions and organizations*

No
 Yes

If yes, please specify:

2. Promoting in the community the awareness that at some point we may have to take care of someone and be prepared for when this happens?

Examples of ways to assess this benefit are:

- i) to measure the number of workshops, talks, educational, psycho-pedagogical and awareness-raising activities on these topics and number of attendees,*
- ii) to evaluate changes in the perceptions regarding the care of the participants, the population.*

No
 Yes

If yes, please specify:

3. **Generating spaces (and providing tools) to talk about grief, normalize it, and address it from the community so as not to depend on health professionals?**

No
 Yes

Examples of ways to assess this benefit are:

- i) To conduct satisfaction surveys after workshops or after meetings with attendees and speakers,*
- ii) to measure the number of initiatives that deal with this topic, such as death cafes*

If yes, please specify:

4. **Encouraging a collective responsibility in society to accompany and support each other, particularly at the end of life?**

No
 Yes

Examples of ways to assess this benefit are:

- i) to conduct a qualitative analysis of interviews with a random sample,*
- ii) to investigate the social support that informal caregivers receive when caring for someone at the end of their lives.*

If yes, please specify:

5. **Improving the quality of patient care by getting closer to patients, listening to them, respecting their autonomy, supporting them, and addressing their needs?**

No
 Yes

Examples of ways to assess this benefit are:

- i) to conduct patient and family satisfaction surveys,*
- ii) to conduct questionnaires at comparative times on well-being and quality of life (e.g. Euro QoL)*

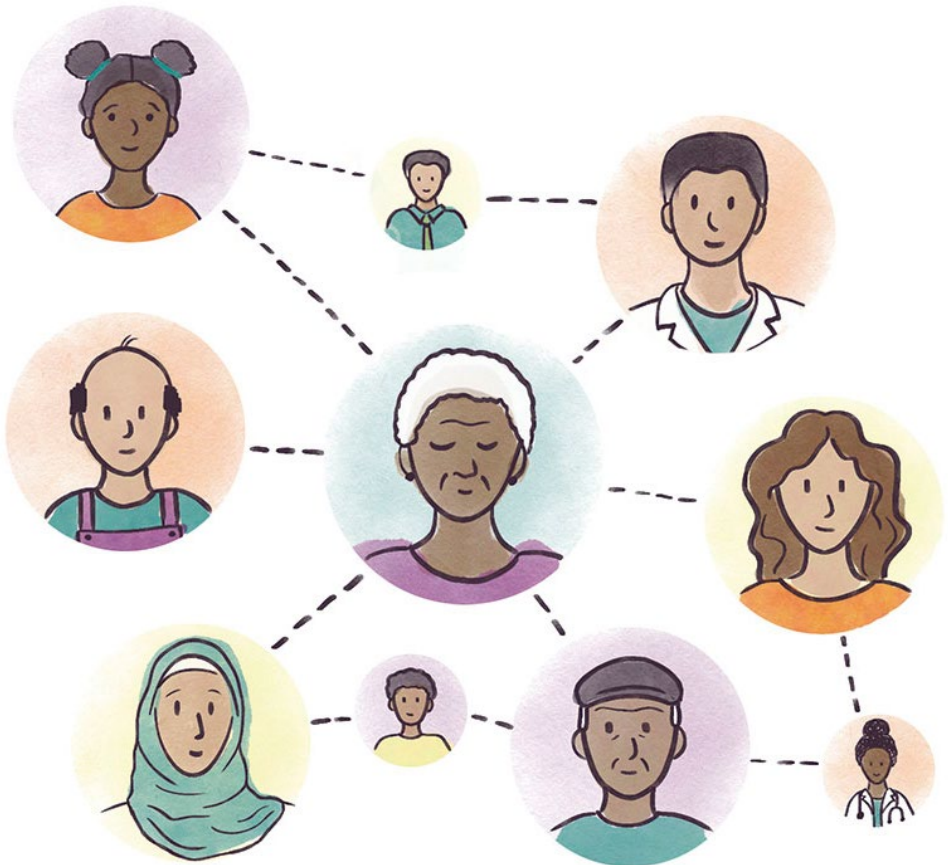
If yes, please specify:

6. Training the general community (children and young people, caregivers, patients, and health care professionals) in compassion, caregiving, end of life, death, and bereavement, independent of whether they need these skills at present or may need them in the future?

No
 Yes

Examples of ways to assess this benefit are:
 i) to measure the Death Literacy Index
 ii) to assess significant learning

If yes, please specify:



Context-adapted appropriate benefits responding to local needs

As recommended in other project development frameworks (e.g. Log Frame approach) and based on the local/regional needs assessment, additional benefits should be agreed upon through focus group work and should be integrated into the assessment.

You can insert these benefits here and, ideally, report to our research group on your specific findings.

No

Yes



If yes, please specify:

No
 Yes



If yes, please specify:

No
 Yes



If yes, please specify:



todos con Vos
Buenos Aires

