Welcome!

We will begin momentarily

Examples of Community Connector Programs

Facilitator: Bonnie Tompkins, BPH
Presenters: Barbara Pesut, Jessie Williams, Camila Ronderos Bernal, Dr. Julian Abel

Date: June 27, 2023

Territorial Honouring

The Palliative Care ECHO Project

The Palliative Care ECHO Project is a 5-year national initiative to cultivate communities of practice and establish continuous professional development among health care providers across Canada who care for patients with life-limiting illness.

Stay connected: www.echopalliative.com

The Palliative Care ECHO Project is supported by a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.

Health Canada Santé Canada

Project ECHO Palliative Care - Canada BY Pallium Canada PHPCI Public Health Palliative Care International

Introductions

Facilitator

Bonnie Tompkins, BPH
Compassionate Communities National Lead, Pallium Canada
PHPCI Council Member

Presenters

- **Barbara Pesut** PhD RN - School of Nursing, Principal Research Chair Palliative and End-of-Life Care
- **Jessie Williams** - Manager, community programs, Community Care & Wellbeing
- **Camila Ronderos Bernal** PhD - Executive director of Fundación Keralty in Colombia and Keralty Compassionate Communities in the US
- **Dr. Julian Abel** - Director, Compassionate Communities UK

Conflict of Interest

Pallium Canada

- Charitable Organization
- Partially funded through a contribution by Health Canada
- Generates funds to support operations and R&D from course registration fees and sales of the Pallium Pocketbook

Facilitator/Presenter

- **Bonnie Tompkins:** Works for Pallium Canada and a council member of PHPCI.
- **Barbara Pesut:** No conflict of interest.
- **Jessie Williams:** No conflict of interest.
- **Camila Ronderos Bernal PhD:** No conflict of interest.
- **Dr. Julian Abel:** No conflict of interest.

Welcome and Reminders

- For comments, please use the chat function.
- For questions, please use the Q&A function, these questions will be addressed at the end of the session.
- This session is being recorded—this recording and slide deck will be emailed to registrants within the next week.

Acknowledgement

This webinar is co-hosted by **Public Health Palliative Care International.**

W: www.phpci.org E: info@phpci.org

Who is PHPCI?

Our Aims

- Health promotion
- Educational and practice
- Biennial conferences
- Research and evaluation
- Professional links and knowledge exchange
- Global forum
- Support, network and mentor students
- Collaborate effectively

Nav - CARE

Canada

www.Nav-CARE.ca

Barb.pesut@ubc.ca

The Nav-CARE program provides **specially trained, mentored and experienced** volunteer navigators to work with persons living with declining health and their families in the home to improve quality of life.

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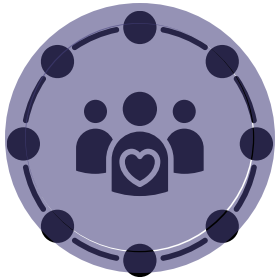
Key Principles of the Nav-CARE Program

Provide Early Support

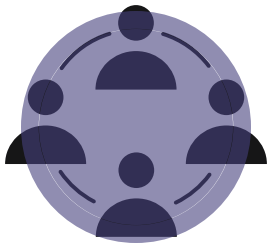
Adopting a palliative approach to care

Build social connections

Fostering compassionate communities



Quality of Life



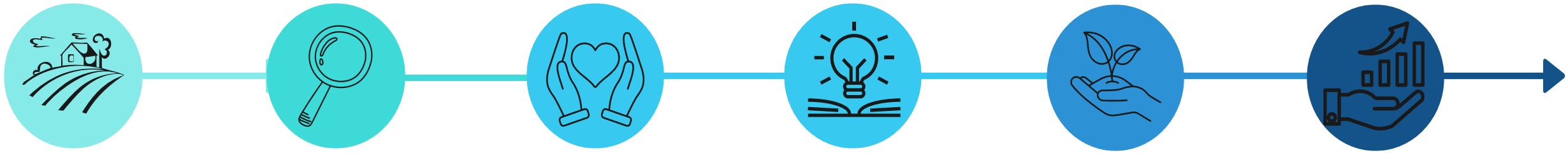
Build volunteer capacity

Building upon the strong tradition of volunteering

Optimize access to resources

Connecting people to relevant resources within their communities

Nav-CARE Development



https://nav-care.ca/our-story/

How Nav-CARE has been funded

Financial contribution from
Avec le financement de

Health Canada / Santé Canada

Max Bell Foundation

PWIAS
PETER WALL INSTITUTE FOR ADVANCED STUDIES
THE UNIVERSITY OF BRITISH COLUMBIA | VANCOUVER

CIHR IRSC

vancouver foundation

Canadian Frailty Network | Réseau canadien des soins aux personnes fragilisées

Canadian Cancer Society / Société canadienne du cancer

BC Centre for Palliative Care

UNIVERSITY OF ALBERTA

THE UNIVERSITY OF BRITISH COLUMBIA

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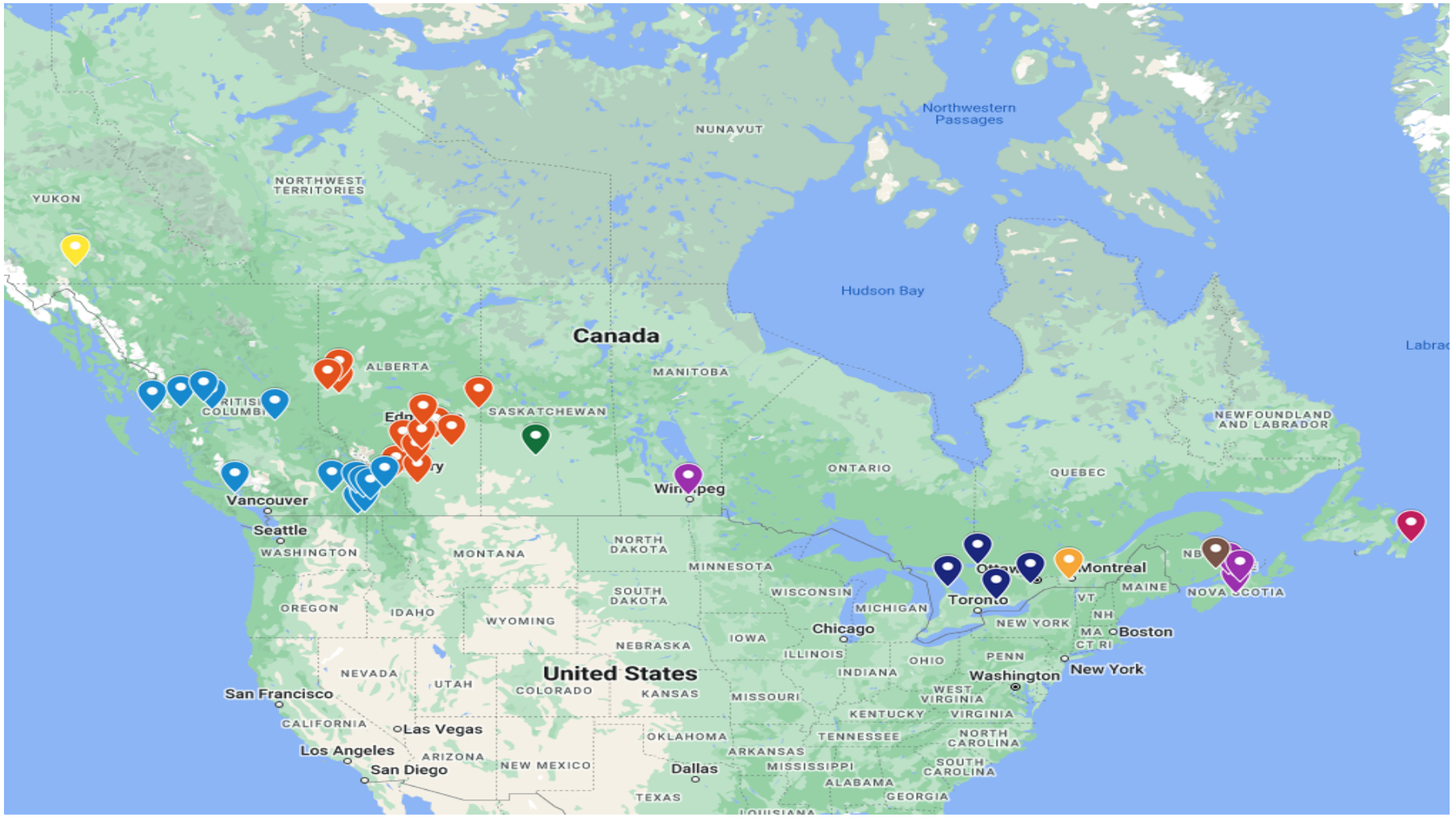
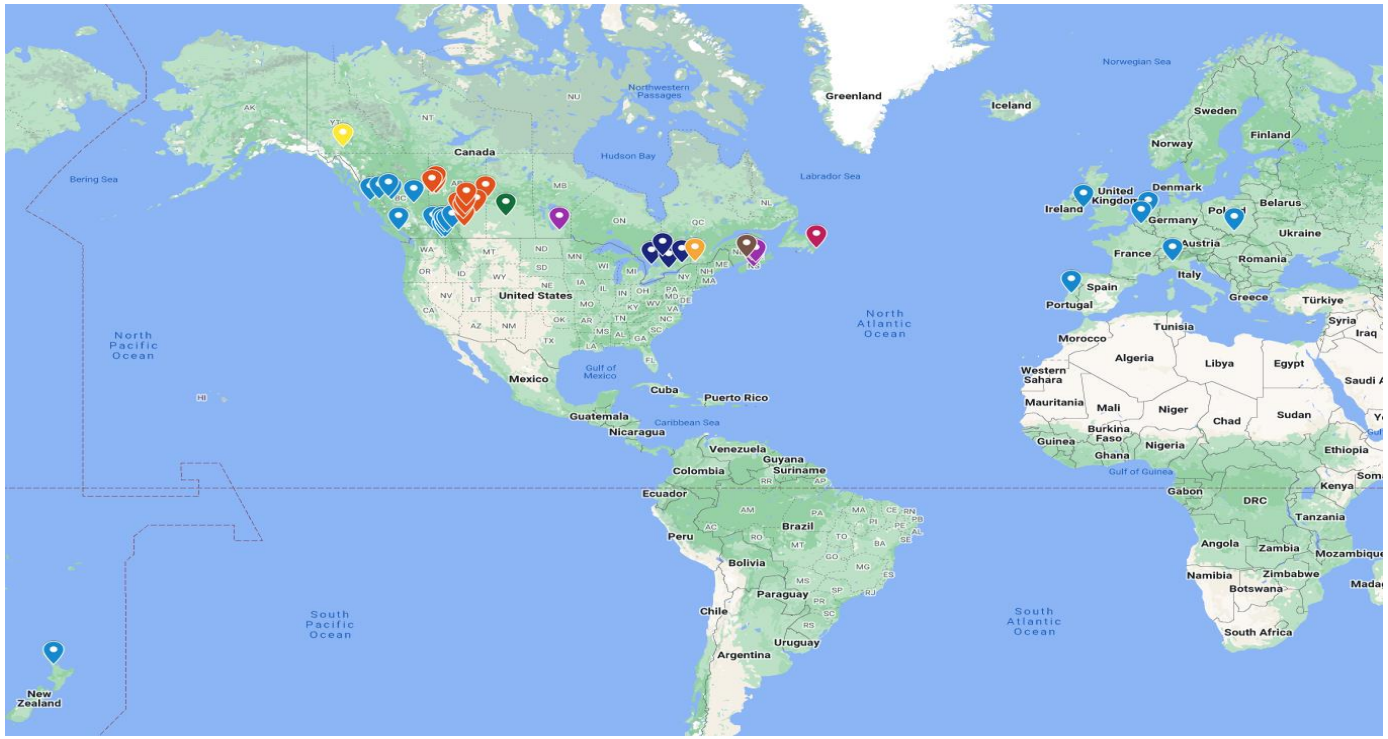
Geography Served: Contribution from Health Canada



European Expansion
"EU Navigate"

Funded by the European Union (Grant no 101057361)
End of Life Care Research Group Belgium



Who Does Nav-CARE Serve?

Persons:

- Facing loss and declining health
- Experiencing complex treatments and decisions
- Feeling lonely or socially isolated
- Living in urban, rural or remote locations
- Living at home, in long term care, or assisted living

Family Caregivers of Persons Living with Dementia (new!)

How people are referred

Self-Referral

Family and Friends

Health Care Providers

Nav-CARE volunteers

Experienced Volunteers:

Average Age = 63, Predominantly Female (87%), 50% have greater than 10 years of volunteer experience**.**

Time Commitment:

1-2 hours per week

Managed:

Volunteer Coordinator mentorship and support. Hub huddles for Volunteer Coordinator Support

Volunteer Preparation: Competency-Based Navigation Education

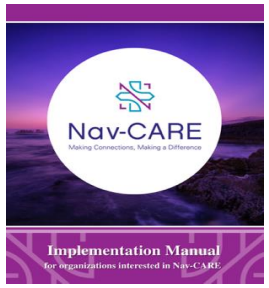
Volunteers learn how to:

- **Address** quality of life concerns
- **Advocate** for clients and families
- **Facilitate** community connections
- **Promote** active engagement
- **Support** virtual navigation

Model: What Do Nav-CARE Volunteers Do?

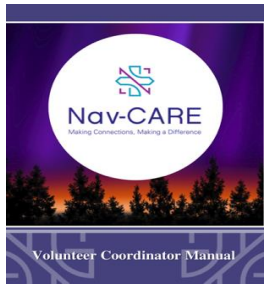
- **Visit in the home every 1-2 weeks.**
- **Develop relationships** with persons. They have the luxury of time to hear stories, to share a cup of tea, or to take a walk. In doing so, volunteer navigators "*bring the community to them*."
- **Assist with tasks** that persons with declining health find challenging to navigate.
- **Find** the resources and local services that assist persons in meeting their daily needs.
- **Listen** as persons make the transitions and decisions that arise out of declining health.
- **Provide a safety net** for those living at home alone and without family nearby.

Nav-CARE Toolkit



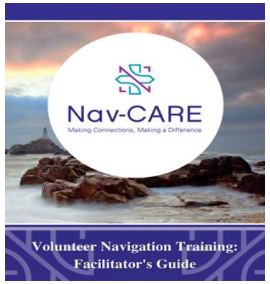
Implementation Manual

This manual is designed for organizations who are considering implementing the Nav-CARE Program. The purpose of this manual is to help organizations consider whether Nav-CARE is a good fit.



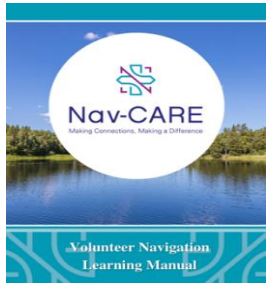
Volunteer Coordinator Manual

This manual is designed to assist volunteer coordinators with the successful implementation of a Nav-CARE program in their community.



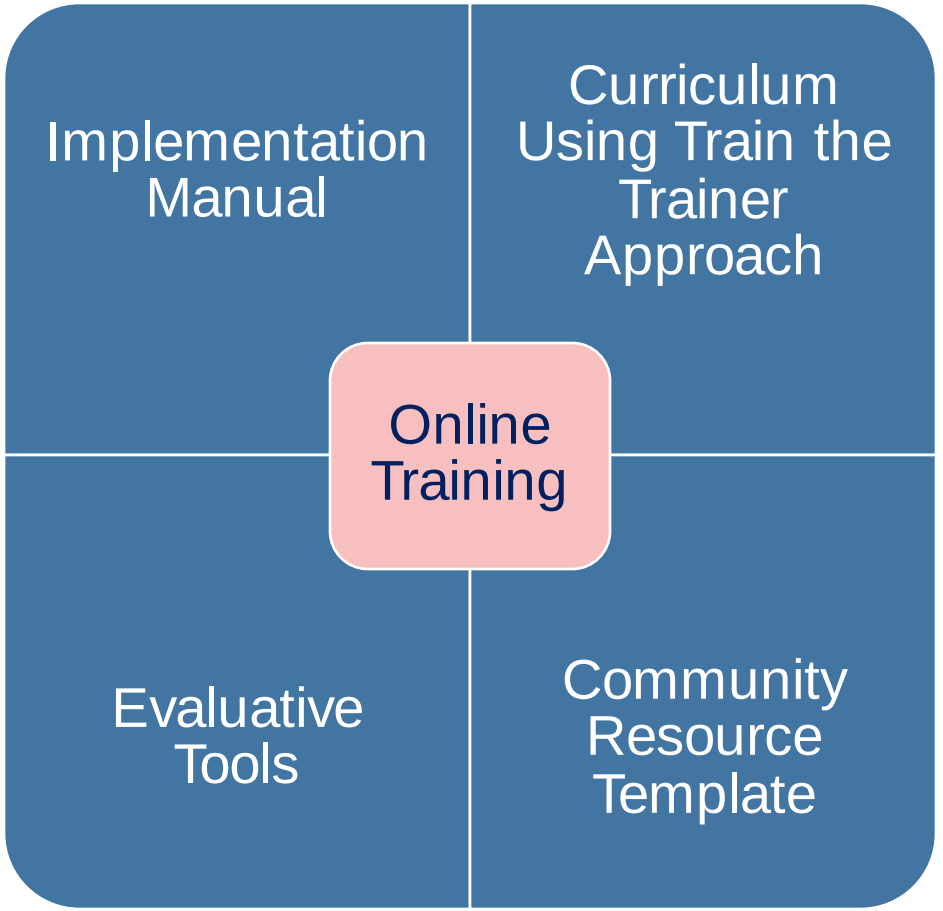
Volunteer Navigation Training: Facilitator's Guide

This manual is designed to assist trainers with the delivery of the Nav-CARE volunteer navigation education. It is meant to be used alongside the Volunteer Navigation Learning Manual and the online Volunteer Navigation Training.



Volunteer Navigation Training: Learning Manual

This manual covers the information and tools needed to become a Nav-CARE Volunteer Navigator.



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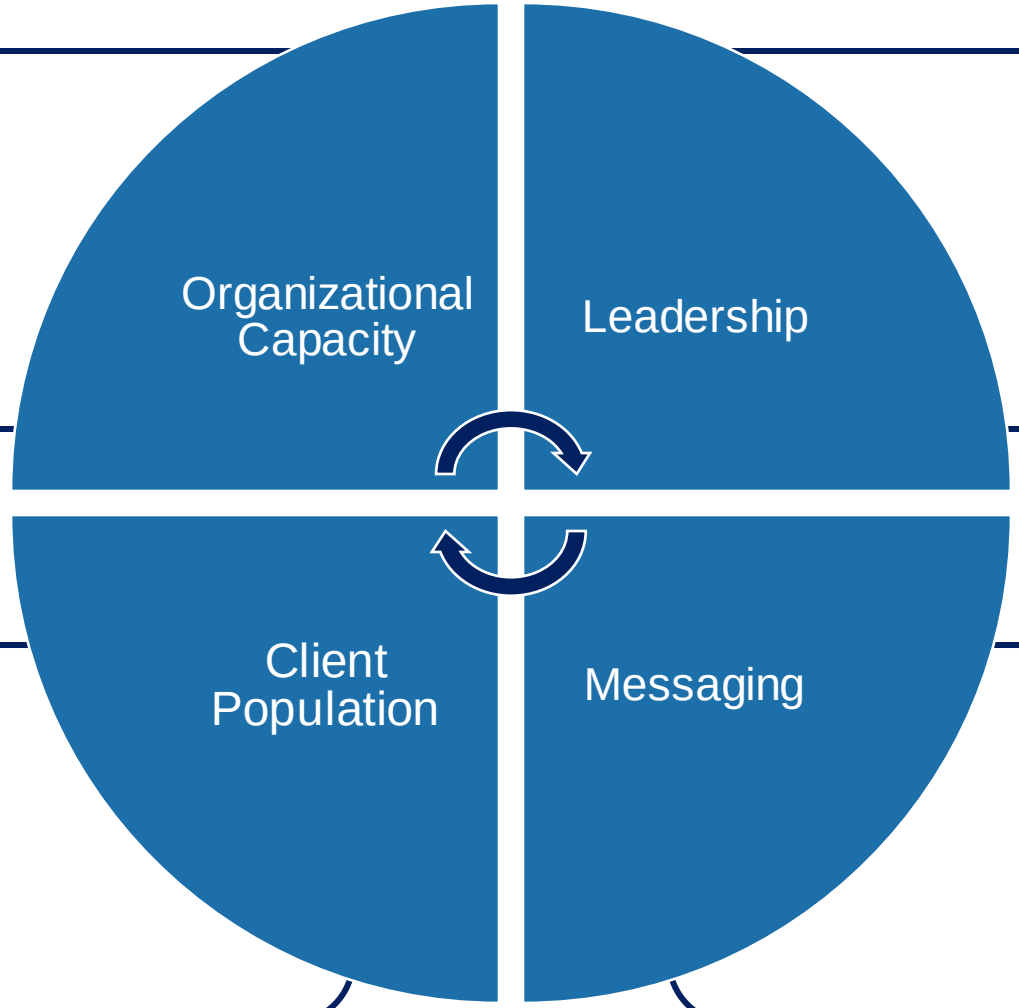
Impact

Clients	Volunteers	Stakeholders
• Statistically significant improvements in awareness of available services, confidence in making decisions, taking care of their illness, and communicating needs to healthcare providers. • Participants rate service as important to their care. • Improved quality of life through tangible benefits that improve their illness experience.	• Good self-perceived efficacy in the role. • Satisfaction in the navigation role. • Development of reciprocal and meaningful relationships.	• Nav-CARE meeting an important need. • Well designed. • Effective leadership, organizational social capital, and adequate financing required for development and sustainability.

Learning to-date



- Reputation in community
- Funding model
- Volunteer pool

- Stability of leadership
- Champion

- Population in need
- Avoiding overlap and competition
- Complexity appropriate to volunteer role

- Clarity around values added
- Avoidance of hospice palliative language
- Targeted strategies for isolated populations

Photo credit: Neil Thomas

Nav-CARE is an option if you have…

- Well-developed mechanisms to support volunteers
- Experienced volunteers willing to dedicate 2-3 hours per week
- Integration with local health and community resources
- Strong champions who are familiar with the goals of Nav-CARE
- Adaptations to Nav-CARE that suit the community context

Community Connector Training and Lead Connector

Australia

Community Connector training and lead connector

SNAPSHOT

GOAL To build capacity in the health system to uptake community connector model as part of compassionate communities approach

FUNDERS Primary Health Networks: Central Queensland, Wide Bay, Sunshine Coast + Northern Queensland (2021 – 2023)

DELIVERED Across 2 x different funders (4 – 6 months)

- Train the trainer workshops (Lead Connectors)
- Community of Practice sessions (online)
- Death literacy education
- Web – based resources
- Prototyping for future health partnerships model to support connector training and resourcing

How did we start?

Learned from Mendip, piloted Health Connectors/Community Connector roles in Australia (2018 – Covid!)

Latest phase: 2021 onwards

1. Invited to present to regional health inter-agencies on the compassionate communities approach to end of life care
2. Identify the champions
3. Proposed a plan based on available budget that would:
    - Establish case for support for future funding
    - Leave participants with tools they can use as community members or health professionals without reliance on funding
    - Tap into the natural motivations of people enlivened to social connection
    - Leave participants with increased death literacy (at the least)
    - Build networks locally, regionally and nationally
    - Address where possible, what the research says about health and community networks

Main Audience for Connector training

- community ‘minded’ individuals
- passionate about engaging with community members on identifying and signposting to supports that either formally or informally address end of life care, grief and bereavement.
- Health and Community individuals

…Retired professional, health or community service professional or caregiver

The training was **not** designed for those working directly with families.

The role of Lead connector

- Coordinate and deliver the Community Connectors workshops:Facilitating regular meet-ups and promote workshops
- Connecting and networking with potential venues and community partners.
- Verifying the contact details for the community directory (where it exists)
- Collecting and sharing evidence of participation and impact; number of conversations, and stories.

❖May deliver as part of a paid role or as a volunteer as they see fit.

❖Beauty of approach is bringing local network together. Decisions made according to local system and culture

❖Leads supported by community engagement officer in health

The Workshops

- 18 workshops x 3.5 hours
- 300 attendees (approx.)
- Group sizes from 7 – 25
- Promotion, advertising and registration managed by PHN

Train the Trainer outline

- Compassionate communities
- Death literacy
- Community connectors
- Lead community connectors
- Our personal and community assets

- How to hold community connector workshops
- Recruiting participants
- Logistics and set ups
- Outline of workshop
- Next steps to grown and sustain the connector Network

Evaluations: What had the most impact on you during the workshop?

The open hearted sharing. The knowledge offered and received.

A room full of compassion (48%)

The amount of connections I did not know about. Changes have to become available in the community (30%)

Clarified community connector tools and processes. Identifying what signposting is and how important it is in my role (22%)

Evaluations: What else might you do after this workshop to strengthen your local compassionate community around end-of-life issues?

Volunteer to help get a community directory together, invite guest speaker to bowling club

Increase my understanding of end of life supports so I can have more informed conversations (45%)

Embed community connector training in staff development with management approval (25%)

Facilitate a dying to know day morning tea ETC (18%)

Challenges:

Lack of clarity with health (funding) partners on:

- What is the ecosystem in which the workshops take place:
  - Place-based, LGA footprint, PHN footprint, local town, professional or special interest group etc

- To what extent should the messaging be adapted for the different audiences (health vis a vis everyone else)
  - Community leaders
  - Health professionals
  - Influencers eg local council members
  - Service organisations
  - Family members and carers with lived experience of end-of-life

Who will be responsible for follow-up actions

For Example:

- The workshop host
- Partner sponsor organisations
- A newly formed community of practice / committee / decision-making group recruited from the workshop or adjacent to the community context of the workshop
- Building an asset directory

What next for us?

- Designing the next phase for the Community Connector model in our own heartland in Sydney's north
- Opening small grants round for other organisations supporting caring at the end of life

Our door is open for:

- delivering train-the-trainer workshops (Lead Connectors)
- Community Connector training for other place-based programs (special sauce is Connector training!)
- Regional and national Partnerships to grow and learn

Compassionate Care Community

Colombia & US

Fundación Keralty

Compassionate Communities By Keralty

Compassionate healthcare

Transforming health care and empowering communities

- Implemented in Colombia and Florida with healthcare services – primary care facilities, hospitals, palliative care services to transform the way we approach our patients and understand their true needs.
- Healthcare services identify needs through different tools – Lubben loneliness scale, circles of care methodology, SDOH screenings – that are embedded to the electronic medical records.
- We work with Community Health workers who identify and connect resources around the different facilities according to the needs being identified with the patients.
- The team does social prescriptions to CHW or to resources according to the needs of the patients.
- CHW do follow up with the patients to make sure they engage with the resources and lead Communities of Wellbeing based on the 6 jewels of health.
- Volunteers lead activities that connect our patients

Compassionate Communities of Care

Colombia Contigo
CIUDADES COMPASIVAS

todos Contigo .org

NEW HEALTH FOUNDATION

Promoting the creation of compassionate communities and cities, that care for each other by promoting compassion, support and solidarity

7	Compassionate cities strengthening social capital
13034	People that have improved their networks of support
111	Expert volunteers that share their knowledge to support care
35	Partnerships with other organizations
20	Communities of care
820	People participating in the communities of care

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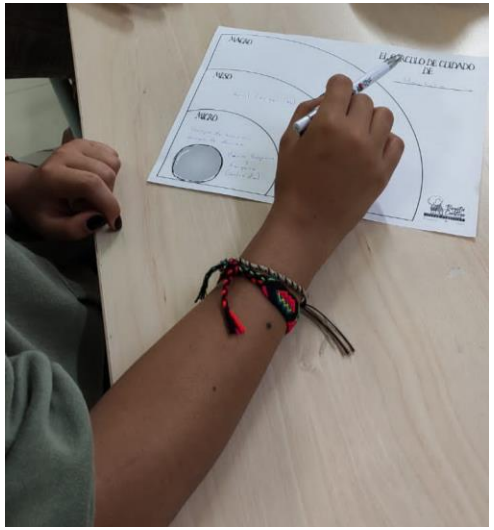
What have we achieved

- Florida
  - 4200 Lubben scales applied to seniors
  - 1084 seniors identified as lonely
  - 45% of seniors receiving a social prescription directly from their doctor
  - 90% of seniors contacted in order to connect to resources or CoW
- Colombia – medical centers
  - 27 medical centers participating
  - 40,000 scales applied
  - 90,000 social prescriptions to resources
  - 21,400 participants in group activities lead with volunteers (400)
  - Cost reduction of around 55% in hospital stays for those patients that were reached by the community approach.



Main Challenges

Within the clinical settings

- Building into the medical practice the need to do loneliness, SDOH or circles of care check ups
- Connecting the medical teams with the WHY of this process – it is not just the responsibility of the CHW
- Traceability and measuring impact

Within the communities

- Breaking the connection of health with the healthcare sector
- Building or rebuilding social capital – trust and connection to care for each other
- Long term commitment of communities and leaders

Citizen Connectors

United Kingdom

Compassionate Communities UK

Structure

- What are citizen connectors?
- Why we are all compassionate – our evolutionary biology
- Treasure maps rather than maps of misery
- The role of citizen connectors

What are citizen connectors?
We are all natural connectors

A citizen connector someone who is an activated community member who

- Knows their community
- Helps to create a warm hearted environment
- Is ready to listen
- Does not try to fix or find solutions
- Offers information about what is going on in the community

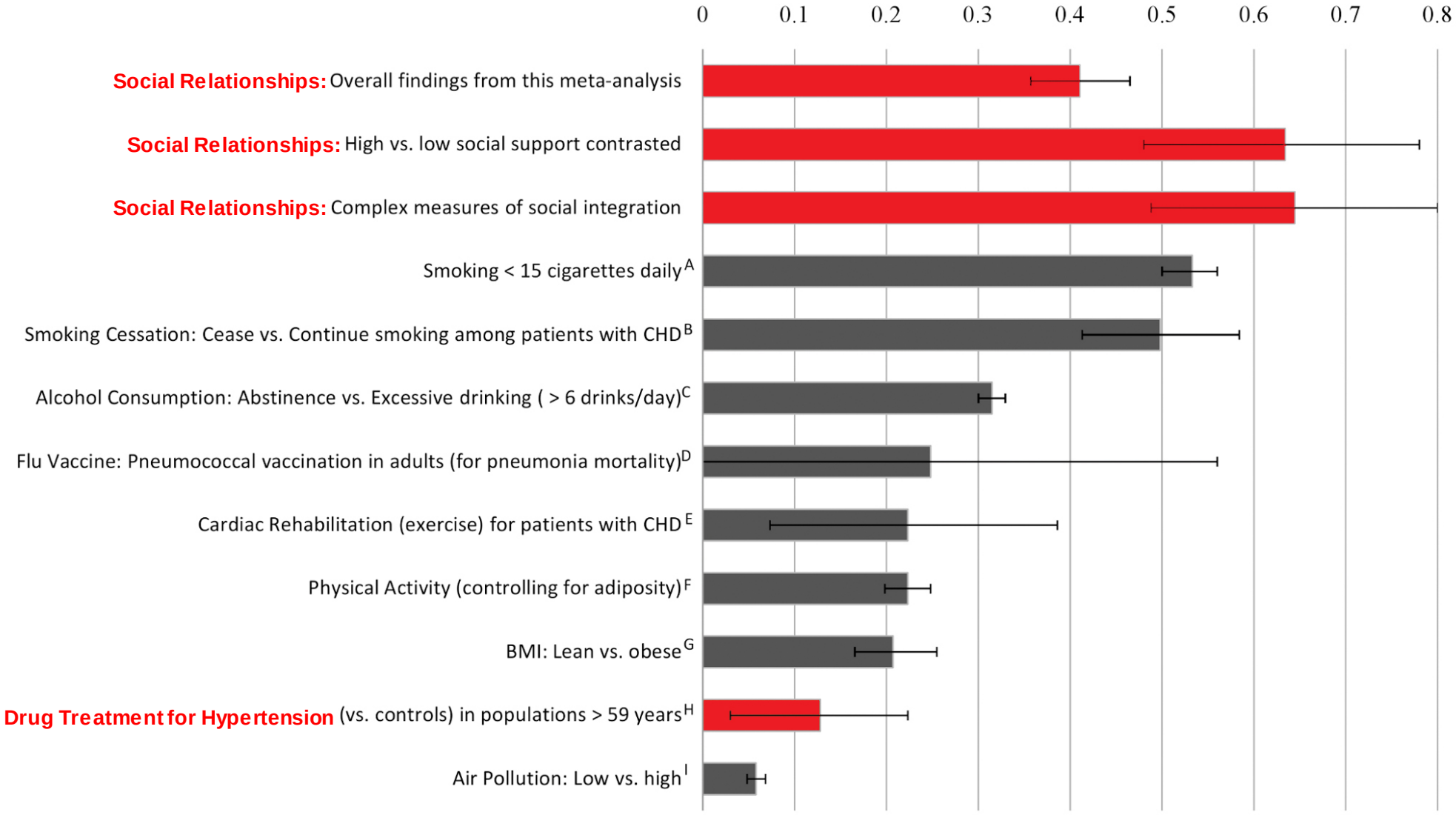
What citizen connectors are not

- People who know the answer
- They are not volunteers
- They do not belong to an organisation

BUT

- Do see themselves as citizens in the context of their community
- Are prepared to help when it is needed and asked for.

1. Comparison of odds (lnOR) of decreased mortality across several conditions associated with mortality.



Holt-Lunstad J, Smith TB, Layton JB (2010) Social Relationships and Mortality Risk: A Meta-analytic Review. PLOS Medicine 7(7): e1000316. https://doi.org/10.1371/journal.pmed.1000316 https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1000316

Humans are basically good and compassionate – Survival of the Kindest

- Because we all have compassionate potential, we can be social, and to be social is to survive
- Evidence is in our evolutionary roots
- Hundreds of thousands of years of human evolution
- Hundreds of millions of years in animal evolution
- Found everywhere, biochemistry, physiology, genomics, behaviour etc

- But we also have an alarm system in us to help us get out of danger.

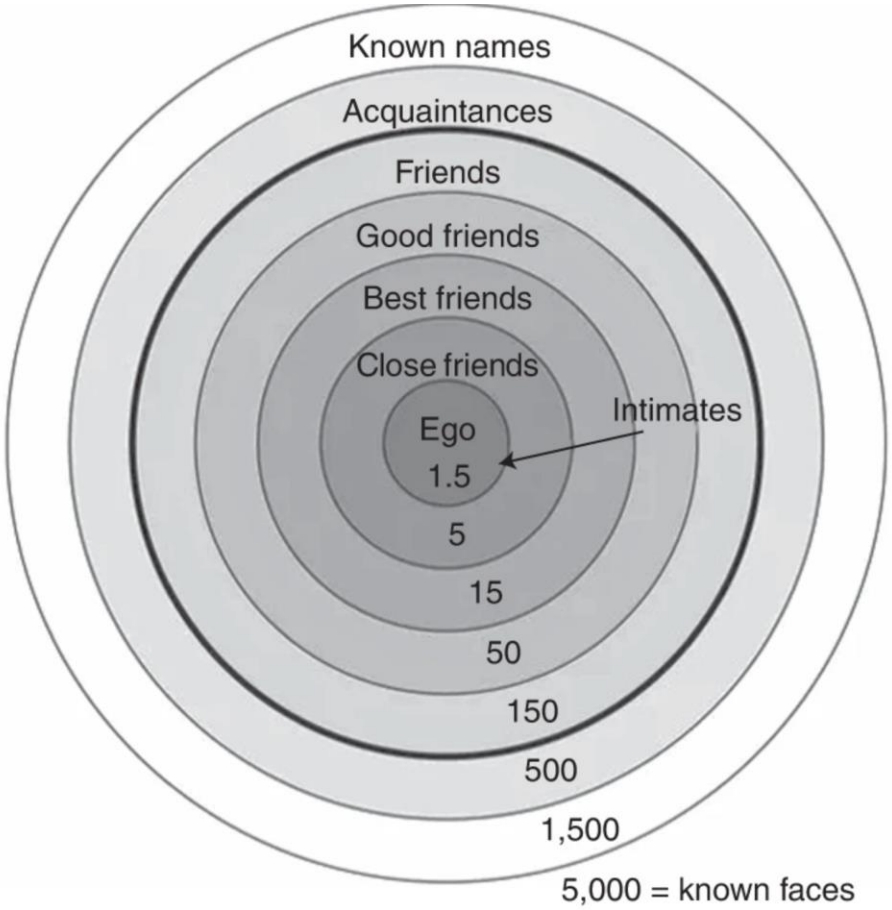
Loneliness is a threat to our survival

- Physiological, biochemical, genomic response to loneliness and physical danger
- Our brains shut down in order to prioritise survival, moving, alertness, change in blood flows and closing down non urgent pathways to our prefrontal cortex
- VERY bad for us when we are chronically lonely – major cause of ill health and death at least equivalent to smoking

Prof Bessel van der Kolk – The Body Keeps the Score

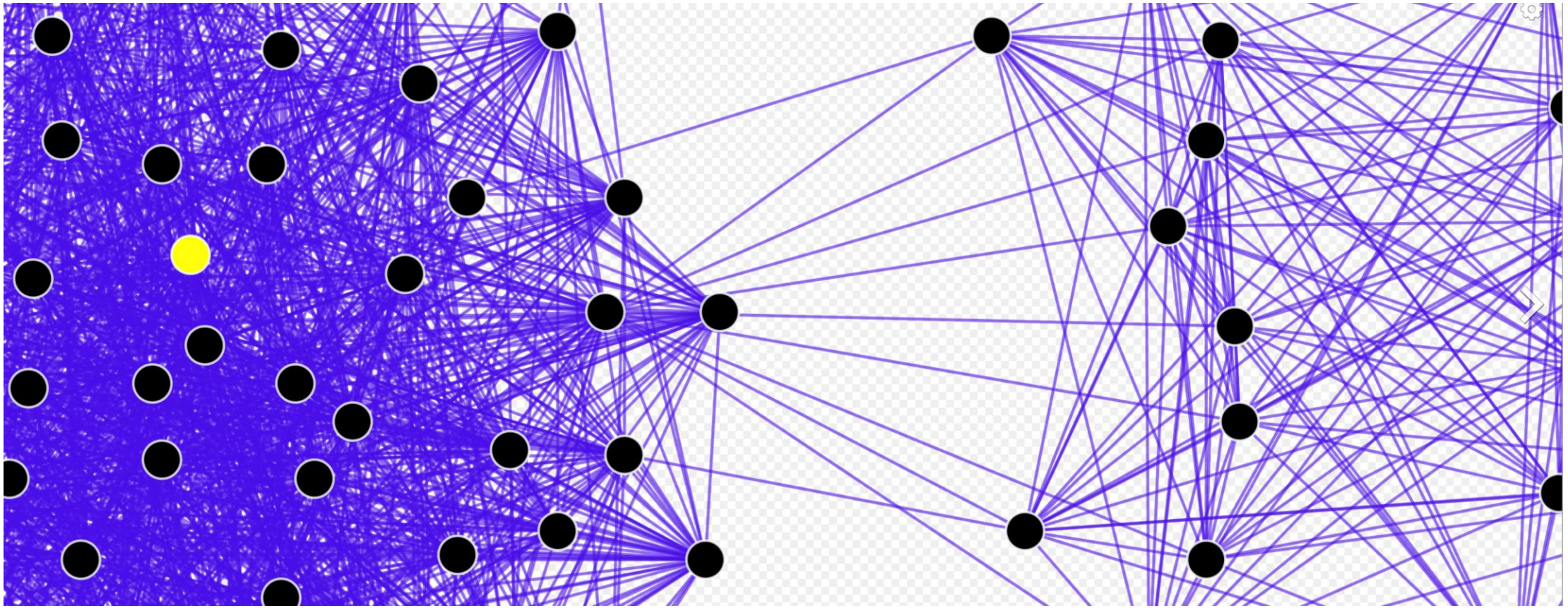
Social support is not the same as merely being in the presence of others. The critical issue is reciprocity, being truly heard and seen by the people around us, feeling that we are held in someone's mind and heart. For our physiology to calm down, heal, and grow we need a visceral feeling of safety.

No doctor can write a prescription for friendship and love. These are complex and hard earned capacities.



Neocortex size as a constraint on group size in primates
RIM Dunbar - Journal of human evolution, 1992 - Elsevier

Networks of relationships



Treasure maps

- Communities can be seen with 2 different lenses

1. Maps of misery, where all the things that are wrong with a neighbourhood are looked for
2. Treasure maps, where what is right with people and place

Treasure maps are the places where warm interactions between people can take place. When looked for, treasures can be found in communities in unexpected places


COMMUNITY ENGAGEMENT
DYING MATTERS WEEK
INCREASING AWARENESS INTERNALLY
INCREASE IN 'DEATH' LITERATURE BEING TAKEN
MY FUNERAL SONG DISPLAY FOR DYING MATTERS 2016
INDUCTION/ MANDATORY TRAINING
BEFORE I DIE I WANT TO BE REMEMBERED DISPLAYS
WORKING ON NATIONAL PROJECTS WITH NCPC/DYING MATTERS
PARTNERSHIPS
DYING MATTERS, CUTLER'S FUNERAL SERVICE, MIDLANDS CO-OP, BRETBY/ LICHFIELD CREMATORIUM, MASE GROUP, SUTTON CANCER SUPPORT CENTRE AMINGTON COMMUNITY CAFÉ NCPC/DYING MATTERS
ADVANCE CARE PLANNING SESSIONS WITH ALZHEIMER'S GROUPS
PARTNERSHIPS
AGE UK BURTON, AGE UK SOUTH STAFFS, TRENT & DOVE, ALZ-HEIMERS SOCIETY, ST GILES STAFF
CIVIL SERVICE LOCAL
HOSPICE CARE WEEK SHOWCASE EVENT!
PARTNERSHIPS
LOCAL PATIENT PARTICIPATION GROUPS (INC. Barton, Tutbury, Uttoxeter)
PALLIATIVE CARE A MUSLIM PERSPECTIVE
HEALTH EVENTS IN THE COMMUNITY
PRESENTIONS ON ADVANCE CARE PLANNING AND THE WORK OF THE HOSPICE IN THE COMMUNITY
BURTON CARIBBEAN CENTRE
PLANNED VISIT TO THE HOSPICE TO UNDERSTAND OUR WORK
DIVERSE PARTNERSHIPS
BURTON CARRIBEAN CENTRE, REHANAH SADIQ
UNDERSTANDING DIVERSE COMMUNITIES
ASHBY DE LA ZOUCH COMMUNITY ENGAGEMENT
PARTNERSHIPS
HOSPICE HOPE
SUPPORTED BY VOLUNTEERS
ALZHEIMER'S HELP POINT
PARTNERSHIPS
AGE UK, ALZHEIMER'S SOCIETY, TRENT & DOVE, CARELINE, HERMITAGE CARE HOME,
HOLLY ROAD SUPPORTIVE CARE CENTRE
PRESENTATIONS TO CHURCH GROUPS ON BEREAVEMENT AWARENESS
CHAPLAINCY PLUS, CHURCH GROUPS
TRAINING FOR ST GILES STAFF ON FUNERAL POVERTY
FUNERAL POVERTY AWARENESS SESSIONS
SHARING INFORMATION WITHIN COMMUNITIES
PARTNERSHIPS
N-POWER, AGE UK BURTON, HOMESTART, BURTON ALBION COMMUNITY TRUST
SKIPTON BUILDING SOCIETY
CONNECTING OTHER HOSPICES WITH ORGANISATIONS
COMPASSIONATE EMPLOYERS PROGRAMME WITH NCPC
BEREAVEMENT AWARENESS IN THE WORKPLACE
BEREAVEMENT HELP POINTS
REDUCING SOCIAL ISOLATION
ENABLING THOSE SUPPORTED TO THEN GO ON TO SUPPORT OTHERS
VOLUNTEER LED
PARTNERSHIPS
CRUSE, DOVE SERVICE, STAFFORDSHIRE FIRE SERVICE, CITIZENS ADVICE, SACRED HEART CHURCH, QUEEN'S HOSPITAL
CREATING COMPASSIONATE COMMUNITIES
ST GILES HOSPICE WELL BEING PROGRAMME
PARTNERSHIPS
AGE UK BURTON, AGE UK SOUTH STAFFS, LICHFIELD FIRE SERVICE, BROMFORD HOUSING, BARCLAY'S DIGITAL EAGLES
BRINGING OTHER ORGANISATIONS TOGETHER
REDUCING SOCIAL ISOLATION
SUSTAINABILITY EXERCISE CLASSES EVERY WEEK AT AGE UK BURTON
LOCAL COMMUNITY SUPPORT GROUPS
ST GILES COMPUTER GROUP
LUNCH BOUGHT BY COMPUTER GROUP TWICE A WEEK
CRAFTY PALS
MERE GREEN LUNCH GROUP
WHITTINGTON & FISHERWICK GOOD NEIGHBOURS SCHEME
CONTRIBUTING TO HOSPICE BASED PROJECTS
CONTRIBUTING TO VILLAGE COMMUNITY LIFE
PARTNERSHIPS
BIRMINGHAM COUNTY COUNCIL, GARRICK THEATRE, LOCAL COMMUNITY GROUPS
INCOME GENERATION THROUGH SALES OF CRAFTS
REDUCING SOCIAL ISOLATION
INTRODUCING NEW LOCAL PEOPLE TO SUTTON SUPPORTIVE CARE CENTRE
WORKING WITH SCHOOLS & YOUNG PEOPLE
JOHN TAYLOR SCHOOL ART PROJECT
BEFORE I DIE JIGSAW PROJECT
THE FAMILY ROOM GARDEN PROJECT
ELSWICK HOUSE NURSERY SCHOOL TEDDY BEAR'S PICNIC & ARTWORK
WALSALL COLLEGE STUDENTS
TALKING ABOUT DYING WITH YOUNG PEOPLE
PARTNERSHIPS
DE FERRERS SCHOOL, STREETLY ACADEMY, PAULET SCHOOL, RAWLETTS SCHOOL, CHASE TERRACE SCHOOL ETC
RAWLETTS PEER MENTOR SUPPORT GROUP
WORK EXPERIENCE/ SUMMER SCHOOL
TAMWORTH COLLEGE HEALTH AND SOCIAL CARE STUDENTS
MEDICAL STUDENT TRAINING
PHOENIX
SUPPORTING CHILDREN & YOUNG PEOPLE THROUGH BEREAVEMENT
VOLUNTEER LED
PARTNERSHIPS
TAMWORTH BOXING CLUB, BURTON ALBION COMMUNITY TRUST, GARRICK THEATRE

Where do you find treasures

- Cafes, pubs, libraries, Men's Sheds, Women's Sheds, walking groups, running clubs, book clubs, knit and natter, hairdressers, parks, skate park, seaside, dog walks, sports clubs, model railway interest groups, GP surgery waiting areas, coffee areas at work, shops, outside the school gates, watching your children play sport, places of worship etc etc
- Creation of treasures where chatting can happen – friendship cafes, talking cafes, chatty cafes, talking bench.

Treasure mapping

- Who and what are the treasures in your community?
- Where are these treasures?
- What does your treasure map look like?

- Spend the next few minutes drawing a treasure map of your community, your neighbourhood.

Resource Directories

- Resource directories are treasure maps – where you can find great things and where you can look for solutions to problems.
- Local by nature
- Main focus is what are all the things going on in the community, but also includes, as a minor part, charities and services
- https://healthconnectionsmendip.org/mendip-directory/

How to start discovering treasure maps – populating the resource directory

- Community participation –what is possible
- Doing it alone or doing it together – who will you engage with?
- Where does this engagement take place?
- Who is the resource directory for?

What and where are the treasures in your community?

Citizen Connector Training

- Training can take place anywhere - a park bench, a church hall, a community centre
- What is important is that as many people as possible know how to be a citizen connector
- Training therefore has to be easy to access and does not necessarily need to be done in one place
- Citizen connectors are not volunteers but activated citizens

What do citizen connectors need to know?

- Humans are basically good – we all have the potential to be compassionate.
- We are social creatures. To survive we need to have a sense of belonging.
- Communities contain treasures of people and place, waiting to be discovered.
- Listening and not fixing are the key skills of a citizen connector.
- It is possible to be a citizen connector anywhere.

Who should train as a citizen connector?

- Everyone!
- Citizen connectors in all the areas in the compassionate city charter – educational institutions, workplaces, places of worship, neighbourhoods, hairdressers, firemen, police, receptionists, health professionals, café owners, young mums, youth workers, sports coaches etc etc
- Particular attention to be given to having citizen connectors from diverse backgrounds – ethnicity, LGBQT+, homelessness

What happens once someone is trained?

- Citizen connectors are people who simply know how to access information and help
- The key is that they are helpful and kind – willing to share if it is wanted
- Each connector will have conversations in their own way, so need to be free to do so
- BUT
- Stay connected – feedback from connectors is really useful, what is good, what is not helpful and what is absent.

Q & A

Become a member

Join PHPCI and stay up to date - www.phpci.org

- Research
- Resources
- Events

World Hospice Palliative Care Day

Oct 14, 2023

Download your toolkit at www.thewhpca.org

PHPCI's World Compassionate Communities Day is Nov 1, 2023

The two organizations are working together – watch for more details.

Upcoming Conference: Bern Switzerland

Session Wrap Up

- Thank you for joining us!
- Please fill out the feedback survey following the session—a link has been added into the chat.

Thank You

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