CONFERENCE REPORT

National Dementia Conference

Inspiring and Informing a National Dementia Strategy for Canada

MAY 14–15, 2018

Ottawa, Ontario

Public Health Agency of Canada
Agence de la santé publique du Canada

TO PROMOTE AND PROTECT THE HEALTH OF CANADIANS THROUGH LEADERSHIP, PARTNERSHIP, INNOVATION AND ACTION IN PUBLIC HEALTH.

—Public Health Agency of Canada

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On May 14–15, 2018, a National Dementia Conference hosted by the Honourable Ginette Petitpas Taylor was held in Ottawa, Canada. The key messages and ideas summarized in this report are for information only, and are not intended to indicate a consensus of opinion or agreement. In addition, the opinions and views expressed at this conference are those of the participants and do not necessarily reflect the opinions and views of the Government of Canada.

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1.0 Executive Summary

The *National Strategy for Alzheimer's Disease and Other Dementias Act* (the *Act*) came into force on June 22, 2017, and requires the federal Minister of Health or delegated officials, in cooperation with representatives of provincial and territorial (PT) governments, to develop and implement a comprehensive national dementia strategy.

As per the *Act*, activities to be considered in the National Dementia Strategy include:

- Developing specific national objectives.
- Encouraging greater investment in all areas of research.
- Coordinating with international bodies.
- Assisting the provinces in developing and disseminating:
    - diagnostic and treatment guidelines;
    - best practices for improving the quality of life of people living with dementia and their caregivers, including greater integration of care, chronic disease prevention and management as well as coordination of community support and care; and
    - information, to health care professionals and to the general public, on the importance of prevention, management, and early intervention in Alzheimer's disease and other forms of dementia.
- Making recommendations on the development of guidelines for standards of dementia care.

The *Act* also calls on the federal Minister of Health to convene a national dementia conference and establish an advisory board.

On May 14–15, 2018, a National Dementia Conference was held in Ottawa, Canada. The conference brought together about 200 participants from six key stakeholders identified in the *Act*: people living with dementia, caregivers, researchers, health professionals, advocacy groups and representatives from PT governments.

As a key consultation mechanism on the development of the national dementia strategy, the discussions during the conference focused on challenges and opportunities surrounding three overarching themes: 1) care and support; 2) research and innovation; and, 3) awareness raising, stigma reduction and public education.

Participants noted that the National Dementia Strategy should: address stigma associated with dementia; ensure the needs of people living with dementia at different stages along the dementia journey are met; and identify ways to enable quality of life and dignity for people at different stages of the condition. It should: enable collaboration and partnerships among all levels of government, partners and stakeholders, including people living with dementia, their families and those who care for them; enable sharing and scaling up of best practices within and across provinces and territories; consider diversity factors such as cultural, ethnicity and linguistic considerations, rural and remote communities, gender differences, developmental disabilities; and include clear accountability for federal, provincial and territorial governments and other partners.

This report provides highlights of the discussions at the event. The outcomes of the conference and other stakeholder engagement processes to date will be included in a "What We Heard" report, which will be released in the Fall of 2018. All input will inform the development of the National Dementia Strategy.

2.0 About the Conference

As mandated by the *National Strategy for Alzheimer's Disease and other Dementias Act* (the *Act*), the federal Minister of Health held a conference on May 14-15, 2018 in Ottawa, Canada. Approximately 200 participants attended the conference, including representatives from the six stakeholder groups identified in the *Act*:

- people living with dementia;
- caregivers;
- healthcare professionals;
- researchers;
- representatives of advocacy groups; and
- representatives of provincial and territorial governments.

The conference provided an opportunity for participants to share perspectives on the three overarching themes identified in the *Act*, including:

1. care and support;
2. dementia research; and
3. awareness raising, stigma reduction and public education.

For each theme, time was allocated for:

- An opening panel discussion featuring short presentations that was followed by a brief question/answer period.
- Five concurrent dialogue sessions that opened with brief context-setting remarks, included small group table discussions, and wrapped up with each table presenting a summary to the full group.
- A summary of the highlights from each dialogue session and further discussion in plenary.

3.0 Planning

3.1 CONFERENCE PLANNING COMMITTEE

A Conference Planning Committee was established to design the content and program of the conference. Membership included two people living with dementia as well as individuals from:

- Alzheimer Society of Canada
- Bayshore HealthCare
- Canadian Home Care Association / Carers Canada
- Canadian Institutes for Health Research (CIHR)
- Centre for Aging and Brain Health Innovation (CABHI)
- Government of Nova Scotia
- Government of Ontario
- Ontario Dementia Advocacy Group (ODAG)
- Public Health Agency of Canada (PHAC)
- University of Waterloo

3.2 CONFERENCE PROGRAM

The provisions of the *Act* provided the foundation for the design of the conference program. PHAC drew on the expertise of the Conference Planning Committee, as well as key dementia stakeholders and representatives of federal, provincial and territorial (FPT) governments to inform the program content.

Special attention was given to the needs of people living with dementia to ensure that an accessible, respectful and comfortable environment was maintained throughout the event, where they would be able to fully engage in the discussions. Activities included:

- Holding four pre-conference workshops for participants living with dementia to familiarize them with the conference location, program and discussion topics. Participants were able to review and consider the different topics, allowing them to prepare in advance of the conference.
- Consulting people living with dementia on the selection of the conference venue and using the *Murray Alzheimer Research and Education Program (MAREP): A Changing Melody Toolkit* to assess the space in order to limit distractive elements.

- Using greeters during the conference to help participants living with dementia find their way between the hotel and the conference venue.
- Making a quiet room available to participants living with dementia, for use at any time over the two days.
- Sharing engagement guidelines for group discussions with all facilitators to encourage respectful, constructive dialogue. Throughout the conference, facilitators followed the strategies for good facilitation provided by the Alzheimer Society of Canada's **Resource Guide—Meaningful Engagement of People with Dementia** and the recommendations in the **Person-Centered Language Guide**.
- Including time in the conference program for people living with dementia and caregivers to share their stories.
- Adjusting the length and format of sessions to meet the needs of people living with dementia. This included keeping presentations brief and using an informal, moderated panel format for sharing information in large group plenary sessions.
- Including time for participants to write down their thoughts and record their ideas visually during dialogue sessions. The same process was used for each dialogue session, to ensure consistency, build group confidence and minimize confusion.

4.0 Opening Remarks

> **“We are not equipped for dementia [on reserve]. This is a growing population and we respect our elders especially at their last moment of their life…”**
>
> **Algonquin elder Annie Smith-St. Georges**

The conference opened with welcoming remarks by Algonquin elder Annie Smith-St. Georges, who also shared a personal story about her experiences with the health care system when her father developed dementia in later life. Her personal story underscored existing gaps in needed services in Indigenous communities, including care that is close to home and community, and delivered without discrimination. Annie Smith-St. Georges highlighted the importance of working together to ensure better care for the elderly and people living with dementia.

> **“Imagine a world where a diagnosis of dementia is not met with fear, but with hope and understanding…”**
>
> **Federal Minister of Health, Honourable Ginette Petitpas Taylor**

The federal Minister of Health, Honourable Ginette Petitpas Taylor, welcomed participants and shared how she had been personally impacted by dementia when her mother was diagnosed with the condition. Through her personal story, the Minister highlighted the importance of community resources and education to help family members understand dementia and find the right care and support for their loved ones.

Minister Petitpas Taylor also reiterated the federal government’s commitment to the development of a national dementia strategy that will meet the needs of those living with dementia and their family and caregivers. As a part of this process, the Minister announced the establishment of a new Ministerial Advisory Board on Dementia, including the Board’s co-chairs: Pauline Tardif, Chief Executive Officer (CEO) of the Alzheimer Society of Canada and Dr. William Reichman, President and CEO, Baycrest Health Sciences. Membership is broad, including people living with dementia, caregivers, researchers and advocacy groups working directly with those diagnosed with dementia and health care professionals.

5.0 What We Heard at the Conference

For each theme, conference participants identified a number of challenges and ideas, solutions and opportunities. The discussions are summarized according to the three main themes of the conference program; however, many of the challenges and solutions are relevant to more than one theme.

5.1 CARE AND SUPPORT: SUMMARY OF DISCUSSIONS

5.1.1 Challenges

> **“Once she [the doctor] entered the room, I felt like I no longer existed. She did not look at me, and she spoke with my husband. She told him that I had early onset Alzheimer’s and that I was still doing well. She instructed him to bring me back when I couldn’t dress myself… she treated me with such disrespect…”**
>
> **Phyllis Fehr, Person Living with Dementia,**
> **Board Member of the Dementia Alliance International**

- Participants noted inconsistency in the level of training for health care providers with respect to dementia diagnosis and elderly care across Canada. Some participants, particularly people living with dementia and their caregivers perceived a lack of compassion at the time of diagnosis and inadequate support throughout the continuum of care. Particular examples included:
    - Reluctance to give a dementia diagnosis because of an attitude that “nothing can be done”.
    - A lack of understanding of existing diagnostic tests appropriate for different types of dementia.
    - Inability to help people living with dementia and their families and caregivers access specialists for consultation.

- Inability to connect people living with dementia and their families and caregivers with required supports or resources to live well with dementia.
- A lack of support for people at the end stage of the condition to ensure quality end of life care. It was noted that the discomfort some physicians feel about talking about dying is an additional challenge in this regard.

> **"The assessment process within my care pathway was riddled with anxiety, confusion, long wait times, and an overwhelming lack of understanding of the next steps of care…"**
>
> **Mary Beth Wighton, Person Living with Dementia, Chair of the Ontario Dementia Advisory Group**

- Participants indicated that access to dementia care, services and supports is inconsistent across Canada. This is particularly challenging for Indigenous communities, rural and remote areas, and/or other ethnic, cultural, linguistic groups.
- Participants said that integrated models of dementia care are only available in small urban pockets, and have not yet been assessed in terms of their cost-effectiveness.
- It was noted that people living with dementia and their caregivers, as well as health care providers, have difficulty finding evidence-based, easy-to-understand information and guidelines. While information is available in English and French, more can be done to ensure that tailored, culturally-sensitive information and guidelines are shared in more languages.
- Participants also felt that existing evidenced-based recommendations and guidelines[1] on dementia have not been translated widely into clinical practice. These may need to be reviewed to ensure they are up to date with the latest evidence.

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[1] Since 1989, four Canadian Consensus Conferences on the Diagnosis and Treatment of Dementia led to evidence-based recommendations on the diagnosis and treatment of Alzheimer's disease (AD) and related dementias. The last iteration of the recommendations was updated and published in 2012.

5.1.2 Ideas, Solutions and Opportunities

To address these challenges, conference participants offered the following approaches for moving forward:

- Increase access to compassionate, standardized dementia diagnosis and disclosure across the country by:
  - Improving education/training and updating care and treatment guidelines for family physicians and other health care providers.
  - Improving access to specialist consultations.
  - Using available technologies, such as mobile applications, to reach people in rural/remote areas.
- When appropriate, shift away from acute care service delivery to more integrated, home and community-based care by:
  - Developing and implementing changes in organizational policies and practices that include flexible health system policies, governance models, funding structures and approaches that support or incentivize integrated, inter-professional care. This includes increasing the health care system's capacity for change management and ability to move evidence into practice.
  - Adapting community centers to deliver health promotion activities, including intergenerational activities that creatively connect young people with older generations.
  - Expanding day programs and respite care, and offering affordable supportive living options.
  - Working with the provinces and territories to develop strategies to strengthen the home care work force and improve working conditions for front-line staff.
  - Investing in improving and/or replacing aging long-term care facilities and homes across the country that were not built to support people living with dementia.

- Build capacity for person-centered care that respects the rights of people living with dementia and fully involves them (along with their caregivers) in decisions about their own care throughout the condition. This can be achieved by:
    - Investing in continuous skills development and training for those in the health care workforce.
    - Educating people living with dementia and their caregivers about comprehensive care plans and how to be part of a care team.
    - Identifying a dedicated point of contact to develop personalized care plans, coordinate care and provide system navigation support.
    - Involving and empowering front-line care providers (e.g., personal support workers, health care aides) in the care team.
    - Developing holistic assessment tools in care planning, as well as policies and tools to support decision-making.
    - Including person-centered messages that are inclusive, give hope, respect the rights of people living with dementia and support them to live well throughout each and every stage of the condition.
- Strengthen and integrate a palliative approach to dementia care that respects end of life choices, along the continuum of care by:
    - Integrating discussions about advanced care planning throughout each stage of the condition, particularly at time of placement in a care home.
    - Providing proper training and support for end of life care to health care providers in acute care, long-term care facilities, and the communities (e.g., paramedics).
- Develop policies and programs that provide practical and financial support to people living with dementia and to their caregivers, including measures such as:
    - Tax credits for caregivers.
    - Longer compassionate care leave.
    - Expansion of adult day programs and respite care, as well as affordable supportive living options.

- Improve access to evidence-based information and community supports by:
    - Creating a centralized knowledge hub or portal for dementia information, resources and sharing of leading practices that can be easily accessed.
    - Providing stable, consistent funding to programs such as the Alzheimer Society of Canada's First Link program, which connects persons living with dementia and their families to services and supports as early as possible.
- Use federal levers to identify and build on the strengths of leading practices in integrated dementia care across Canada by:
    - Convening PT governments and health care providers to identify common policy questions and the data needed to find solutions.
    - Improving the completeness, consistency, and quality of data collected by institutions, including the interface between community and home care, acute care hospitals and long term care and residential care.
    - Facilitating the development and implementation of flexible health system policies, governance models, funding structures and approaches to physician reimbursement that support and incentivize integrated and interdisciplinary care.
    - Building the needed infrastructure to support the spread and scale-up of promising practices.
- Work with Indigenous communities to improve access to culturally-appropriate dementia guidelines, information, care and community supports.
- Develop accessible and culturally appropriate guidelines on dementia specific to other vulnerable populations, such as those living in correctional facilities and people living with Down Syndrome.

5.2 RESEARCH: SUMMARY OF DISCUSSIONS

5.2.1 Challenges

> **"Everybody, not only researchers, have to speak with research teams to make sure that the real needs, the real challenges are being identified so that we will roll our sleeves together and really move forward in an enhanced way…"**
>
> **Yves Joanette, Scientific Director of the Institute of Aging, CIHR**

- Participants indicated that current funding for dementia research is too low and suggested it should be equivalent to funding for research on other chronic diseases.
- Participants raised the need for targeted and context-specific research focusing on type of dementia, age, gender, geography, language, disability, etc. As well, more research on enhancing quality of life.
- Participants noted that there is a disconnect between the research community and non-researchers that makes it difficult to identify health policy questions and research priorities.
- It is difficult for people living with dementia to participate in research. Barriers to participation include ineffective recruitment methods and/or lack of partnerships with trusted organizations.
- It was proposed that Research Ethics Board requirements of informed consent can present a barrier to participants who are experiencing cognitive decline.
- Participants raised that persistent stigma leads to under-reporting and under-diagnosis; as such, existing data do not tell the full story about the impact of dementia. In particular, data may be under reported in some ethno-cultural groups, Indigenous populations, as well as populations of people with developmental disabilities, and those in the justice system. Data related to the impact of dementia on caregivers is limited and victimization in care homes or hospitals is not captured in surveys.
- It was noted that there are challenges to integrating data across jurisdictions and sectors. This could be due to barriers such as lack of data standards, use of inconsistent indicators, and inconsistent definitions. There are also difficulties translating evidence into policy due to unclear roles/responsibilities or official mechanisms that oversee change management.

- Participants explained that implementing new technologies and innovations for dementia into the health care system is challenging. In addition to an overall resistance to change and the potentially disruptive nature of technologies, there are also legislative and privacy barriers to consider. Funding for procuring new technologies is limited and inflexible funding models make it difficult to adopt/test new approaches to care delivery. Researchers may also have difficulty gaining access to clinical settings to test innovations.
- Participants warned that social innovation is often overlooked in favour of technological approaches to addressing issues.

5.2.2 Ideas, Solutions and Opportunities

To address these challenges, conference participants offered the following ideas, solutions and opportunities for moving forward:

- Include principles and guidelines in the national dementia strategy for bringing together FPT governments to:
    - Build consensus among policy-makers on the policy questions that need to be answered.
    - Facilitate cross-sectoral and cross-disciplinary dialogue and opportunities for collaboration on surveillance and research on health systems and services focused on priority policy questions.
    - Develop nimble systems of data collection and analysis that provide relevant, real-time information.
    - Collect data and share results, lessons learned and promising practices.
    - Develop mechanisms to bridge information into practice.

- Build a business case for investing in dementia research that demonstrates the need for and benefits of research and the social and financial consequences of inaction.
- Improve the completeness, consistency and quality of data collected by institutions.
- Increase investments in targeted dementia research to match the level of other Organization for Economic Co-operation and Development (OECD) countries. Research topics could include quality of life, models of care, integrated care, causes of dementia and innovative methods to share information.
- Use a human rights approach to address issues of inclusion, accountability, and non-discrimination and create supportive research environments where people living with dementia can meaningfully participate as long as possible. This could involve the creation of a national code of ethics around principles of transparency and balancing commercial interests with the public good.
- Translate results of research on brain health promotion and risk reduction into practical, accessible information for different stakeholder groups.
- Develop consistent measures of quality of life in Canada that incorporate both quantitative and qualitative measures, establish standards for quality of life outcomes, ensure indicators reflect the diverse voices and experiences of people living with dementia and caregivers, and modify regulatory frameworks to align with quality of life evidence-based practices.
- Introduce new funding models/methods of remuneration to support the testing and implementation of new innovations in integrated dementia care, such as billing codes that support innovative models of care, pay for performance based on measurement of quality of care; bundled care models, funding by disease state or level of disability and self-managed care.
- Allocate more resources to dementia surveillance and standardize data collection to improve the accuracy and completeness of data. This could involve the creation of a registry of dementia cases and the development of common frameworks for data collection along the full continuum of care that cross jurisdictions and care settings.
- Identify barriers to bringing new innovations and technology into existing practice, such as procurement policies, bid evaluation and reimbursement; lack of collaboration across research and technology sectors and obstacles to knowledge translation.

5.3 AWARENESS RAISING, STIGMA REDUCTION AND PUBLIC EDUCATION SUMMARY: SUMMARY OF DISCUSSIONS

5.3.1 Challenges

> **“[Imagine] the stigma that goes with ordinary care and multiply it by 10 to get a beginning estimate of what happens when people with dementia go into the hospital…”**
>
> **Kenneth Rockwood, Professor of Medicine and Alzheimer Research, Dalhousie University**

- Participants noted that, unlike physical disability, cognitive impairment cannot be easily identified, and there is wide variability in public awareness and understanding related to the condition.
- Participants felt that people are afraid, impatient, disrespectful or paternalistic when interacting with a person living with dementia. In particular, people may focus on their condition instead of seeing their strengths, capacities, interests and aspirations.
- Participants reported experiencing stigma within the health care system at the time of diagnosis in the physician’s office, when receiving care at home/in the community, and when living in supportive housing or long-term care.
- Participants explained that some people living with dementia are not comfortable with wearing or carrying recognizable symbols of dementia, because they feel they might be discriminated against.
- Participants noted that there is limited awareness of the ways to reduce the risk of or help prevent or delay the onset of dementia and the links between mental health and dementia. There is also no central location for sharing information or resources broadly with the public or between health care providers.
- Participants warned that awareness raising of chronic diseases tends to be done in silos, leading to a potential duplication of efforts and inefficient use of resources.
- It was noted that funding for brain health promotion is limited.

- Participants felt that advancing dementia-friendly communities is challenging due to inconsistent branding and some confusion with parallel initiatives that may not be working together. As a result, people don’t understand the definition of a dementia-friendly community and may confuse it with other “friendly” community initiatives, such as Age-Friendly Communities. In addition, more evidence is needed about what aspects of dementia-friendly communities have greatest impact in order to guide policy development and resource allocation, and to incentivise buy-in from the community and businesses.

5.3.2 Ideas, Solutions and Opportunities

To address the identified challenges, conference participants offered the following ideas, solutions and opportunities for moving forward:

- Coordinate a large-scale, targeted and culturally sensitive, Pan-Canadian dementia awareness raising campaign under the leadership of PHAC that focuses on stigma reduction, risk reduction, and inclusion. The campaign should include core messages about giving hope, living well, respecting rights, and seeing the whole person, as well as stories of lived experience. A nationally-recognized symbol/color for Alzheimer’s and dementia could be used and partnerships could be built with celebrity champions and the private sector to increase funding and reach. Any public education or awareness campaign should be integrated with efforts across different chronic conditions with common modifiable risk factors.
- Increase access to consistent quality brain health promotion resources and programs in all communities, especially in rural/remote communities.
- Create a central knowledge hub where everyone can go for reliable, vetted, evidence-based information, educational resources and tools.
- Standardize basic competencies for dementia care and embed them within entry level academic health care professional training programs.
- Identify clear roles in the national dementia strategy for federal, PT and municipal governments and provincial/municipal associations for advancement of dementia-friendly communities.

6.0 Cross-Cutting Issues

In addition to the three overarching themes of the conference program, participants identified challenges and opportunities related to the following issues across the three main conference themes:

6.1 INCLUSION AND ENGAGEMENT OF PEOPLE LIVING WITH DEMENTIA AND CAREGIVERS

Throughout the two day event, participants emphasized the critical role of diverse voices of people living with dementia and those who care for them in discussions about dementia research, programs and interventions as well as the design of systems of care and strategies for awareness raising/stigma reduction. Including stories of peoples' lived experience recognizes the expertise they bring to the discussion and is a powerful tool to change attitudes.

The engagement of people living with dementia and their caregivers will help ensure that research is relevant and focused on the most important priorities. In addition, bringing the patient and caregivers' experiences into health policy and system design can improve quality of care and the supports they need.

Building on "nothing about us without us", the participants highlighted the incredible potential to harness the passion and intelligence of people with lived experience.

6.2 HUMAN RIGHTS

Participants emphasized the application of a human rights lens to the national dementia strategy and the integration of principles of equity, diversity and inclusion throughout. They also signaled the importance of aligning with global and national charters of rights for people living with dementia, particularly with respect to criminal justice.

6.3 DIVERSITY

Participants reported that people in different parts of the country experience inconsistent access to dementia care, services and supports, especially in rural, remote and Northern communities. Information and services tend to be designed to meet the needs of the dominant culture; as such, they do not reflect the diversity of needs and may exclude Indigenous populations and other linguistic and cultural groups. It was also noted that it is important to consider the needs of people at a more advanced stage of dementia and of those with developmental disabilities, whose voices and experience throughout the dementia journey may be overlooked.

Participants called for increased availability and accessibility of diverse, culturally appropriate, inclusive services, including those that are tailored for different socio-cultural groups, and translated into languages other than English and French. Inclusive language should be used when communicating about dementia.

It was also noted that measuring and reporting on service delivery and outcomes for diverse groups are required to ensure equity and inclusion.

7.0 What might success look like?

- Participants highlighted that the National Dementia Strategy should:
    - Identify ways to enable quality of life and dignity for people at different stages of the condition.
    - Enable collaboration and partnerships among all levels of government and dementia partners and stakeholders, including people living with dementia.
    - Be a “whole-of-government” approach that encourages alignment with existing chronic disease prevention efforts with overlapping purposes.
    - Enable the spread and scale-up of promising approaches and best practices.
    - Be flexible enough to consider diversity factors such as culture, ethnicity and language, the needs of rural and remote communities, gender differences and developmental disabilities.
    - Include funding to support the implementation and evaluation of the strategy.
    - Include clear accountability for the federal government, provinces and territories and other partners.

8.0 Next Steps

The ideas and insights shared in the dialogue sessions will guide the development of Canada's first National Dementia Strategy.

In fall 2018, a *What We Heard* report will be shared that will synthesize the sum of input received through this conference and other activities undertaken by PHAC in the lead up to the May 2018 National Dementia Conference.

The National Dementia Conference was a critical milestone. The Public Health Agency of Canada will continue to engage with dementia stakeholders and partners through the newly established Ministerial Advisory Board on Dementia and the FPT Coordinating Committee on Dementia as well as bilateral opportunities to inform the development of the National Dementia Strategy.

9.0 Closing remarks

Minister Petitpas Taylor thanked participants for sharing their experiences, for their honesty, and their engagement in rich and informative conversations. She noted that the voices of dementia champions are needed to challenge the status quo and help to affect change. She highlighted the important role of all partners and stakeholders in addressing the challenge of dementia and emphasized that governments, acting alone, cannot bring about the required changes.

In closing, Minister Petitpas Taylor urged participants to dream big for a future where innovative solutions will provide the best care and where diagnosis will not be met with fear, but with hope.