



Bermudian Charter

of the rights and responsibilities of the elderly and adults in need of long-term care and assistance

Adapted from the European Charter of the rights and responsibilities of older people in need of long-term care and assistance Preamble

Bermuda recognizes and respects the rights of people who become more dependent on others due to ageing, illness or disability to ensure they lead a life of dignity and independence and to participate in our social and cultural life.

Frailty caused by ageing, as well as congenital diseases, neurological disorders, traumatic injuries, and chronic non-communicable diseases, can all result in the need for long-term care or assistance. Dependency on others can occur at any age but inevitably as we grow older the need for care will arise and, with an ageing population, this group of persons is getting larger. Accordingly, recognizing the rights and responsibilities of adults in need of long-term care services and assistance is an investment that benefits Bermuda and needs to be supported through solidarity across generations.

Dependency cannot be the grounds for restrictions on human rights and civil liberties in Bermuda. Any restriction of these rights, if caused by age, illness or disability, must rest on clear legal grounds and transparent legal proceedings, must be proportionate, reviewable, and above all, considered in the best interest of the party concerned. Disregard of and contempt for these rights must be considered unacceptable. Although situations of dependency and vulnerability are complex and can be challenging, people with long-term care needs, their families, and caregivers, should all respect these rights and responsibilities.

The aim of the Charter is to:

- Be a reference document setting out the fundamental principles and rights that are needed for the wellbeing of all those who are dependent on others for support and care due to age, illness or disability.
- Raise awareness for individuals and the community of people's fundamental rights and responsibilities who have long-term care needs and foster best practices.
- Complement and support other measures which are already implemented or in development.

The Charter was developed based on international and local standards¹. These rights are not fully respected today and principles not always upheld, however we must work towards achieving them. This is not just the responsibility of Government; everyone in our community has a role in upholding the rights, principles and responsibilities in the Charter and working towards their full implementation.

The EU Charter on the Rights and Responsibilities of Older Persons is complemented by a guide to support stakeholders to understand and help uphold its principles and serves as a helpful tool for Bermuda.

Article 1

Right to dignity, physical and mental well-being, freedom and security

If you depend on others for support and care, you continue to have the right to respect of human dignity, physical and mental well-being, freedom and security.

In particular, you have the right to:

- 1.1 Respect for your human dignity and welfare, regardless of your age, race, colour, national or social origin, financial means, beliefs, sex, sexual orientation or identity and the degree of care and assistance that you require.
- 1.2 Respect for and protection of your physical, sexual, psychological, emotional, financial and material welfare.

Physical well-being

- 1.2.1 Respect for and protection of your physical well-being and safeguarding from any form of physical abuse, which includes: maltreatment and neglect, malnutrition and dehydration, exhaustion, excessive cold or heat, and any preventable physical illness.

- 1.2.2 Protection from any form of sexual abuse or mistreatment.

Psychological and emotional well-being

- 1.2.3 Respect for and protection of your psychological and emotional welfare and protection from any form of psychological or emotional abuse or mistreatment.
- 1.2.4 Expect that others will not willingly cause you to feel distressed, upset or feel negative or depressed.
- 1.2.5 Be protected from any attempt to separate you from another person whom you wish to be with.

Financial and material security

- 1.2.6 Be protected against all forms of financial and material abuse.
- 1.2.7 Expect that those who look after your financial and material assets will do so in your best interest, if you are not able to do so yourself.
- 1.2.8 Retain your personal possessions until you willingly decide to give them up or until your death. You have the right to protection against being forced to change your will or give up any financial or material means that are rightfully yours.

Protection against medical and pharmaceutical abuse

- 1.2.9 Protection from all medical and pharmaceutical abuse, maltreatment and neglect, including: inappropriate, unnecessary or excessive medical treatment or drug use or denial of treatment

Neglect

- 1.2.10 Protection from neglect and lack of diligence in providing support, care or treatment.
- 1.3 Protection against threats of any nature. You should be enabled to feel safe and secure in your surroundings and with the people around you.
- 1.4 Have access to support services to support those at risk and unable to safeguard their own health and welfare.

Article 2

Right to self-determination

If you depend on others for support and care, you continue to have the right to make your own life choices and to respect for your free will. This right extends to an appropriate third-party of your choice.

Freedom of choice

- 2.1 You have the right to lead a life which is as self-determined and independent, as your physical and mental capacities permit, and to receive advice and support in order to do so.
- 2.2 You have the right to expect that your opinions, wishes and choices are respected by those around you even if you are not able to communicate eloquently. You have the right to be consulted and participate in any decision-making processes that affect you. You should be able to choose a place to live that is adapted to your needs, whether in your own home or in formal care settings.
- 2.3 You have the right to retain control of your property and income, and handle your own financial and legal business and transactions with the authorities. You should receive the support you require to do this.

¹ The Charter was adapted from the European Charter of the rights and responsibilities of older people in need of long-term care and assistance. See Appendix for resources used for adaptation of the Charter.

Support for decision-making

- 2.4 You have the right to nominate an appropriate third-party to take decisions and advocate on your behalf.
- 2.5 You have the right to ask for a second opinion on your health situation before following a course of medical treatment.
- 2.6 You have the right to be given sufficient time to consider your decisions carefully, to access relevant documents, and to make your choices having received independent information, advice and guidance.
- 2.7 In the event that you are unable to take decisions for yourself or express yourself at a later date, you have the right to leave advance instructions on decisions relating to your care, to be carried out by an appropriate third-party. Your wishes should be respected at all times even when communicated non-verbally or through the third-party of your choice.

Restraints to your self determination

- 2.8 You may not be subject to any form of physical or chemical restraint unless it is a proportionate response to a risk of potential harm. In which case, it must be determined to be in your best interest through a transparent and independently verifiable process that can be reversed. Assessments of your level of mental capacity to make decisions should not be absolute nor enduring and should be re-evaluated regularly.

Article 3

Right to privacy

If you depend on others for support and care you continue to have the right to respect for and protection of your privacy and intimacy.

Right to private life

- 3.1 You are entitled to respect for your need for privacy. You should have the opportunity for time and space alone, or with persons of your choice, if you so wish.
- 3.2 Your personal space must be treated with respect regardless of where you live and the degree of care and assistance that you require. It should be the goal of all involved in your support, care and treatment to avoid any restrictions to your privacy or respect for your right to intimate relations.
- 3.3 Respect for your privacy is also reflected in the consideration given to your feelings of modesty. You should be treated by caregivers with sensitivity and discretion.

Right to private information and communication

- 3.4 You have the right to privacy of correspondence. Your letters or electronic mail may not be received, opened or read by third parties without your consent. You have the right to make telephone calls in private.
- 3.5 Your right to privacy must also be reflected in the confidential handling of your data and documents. Your personal data are protected by law.
- 3.6 You have the right to expect that discussions about your condition, care and treatment – whether held with you or between appropriate third-parties are handled with sensitivity and discretion, and with respect for your privacy.

Article 4

Right to high quality and tailored care

If you depend on others for support and care you have the right to access high quality, care, support and treatment tailored to your personal needs and wishes.

Quality of care

- 4.1 You have the right to access high quality and timely health and long-term care services. They should be adapted to your individual needs and wishes and without discrimination of any kind.
- 4.2 You have the right to be attended to by people who have the skills required and adequate support to respond to your need for assistance, care and treatment. Whether you are cared for by professionals, family members or other trusted individuals, they should have received and should continue to receive technical, structural and financial resources, and the specialized training and guidance necessary to provide them with the assistance they need.
- 4.3 You are entitled to benefit from measures to prevent any deterioration of or to bring about an improvement in your condition, and to promote your independence to the greatest extent possible.
- 4.4 You have the right to expect that all individuals, institutions and professional bodies involved in your care, support and treatment should communicate and cooperate with one another and closely align the services they provide to ensure that they are in your best interest.
- 4.5 You have the right to expect timely support for your daily needs from services you are accessing.

Tailored care

- 4.6 You should receive clear information about the type and costs of care you require from all services providers. Contracts should be in place for care services and must be explicit with this information, as required for care homes. Information about your rights and responsibilities with all services should be clear and transparent.
- 4.7 You have the right to move freely within your surroundings. You should be given support and encouragement for your mobility.
- 4.8 You are entitled to expect that aspects of your background and past lifestyle that are important to you are taken into consideration in your care provision.

Article 5

Right to personalized information, advice and informed consent

You have the right to seek and receive personalized information and advice about all of the options available to you for care, support and treatment in order to be able to make informed decisions.

Right to access to personal and personalized information

- 5.1 You have the right to be informed about your state of health and the available treatment and care options. This should include information and advice about the chances of success or failure, potential effects of medicines, examinations or any other medical intervention on your physical or mental health and daily life, and available alternatives.
- 5.2 You and a third party of your choice continue to have the right to access your personal medical data and to request the opportunity to inspect all documents relevant to your health.
- 5.3 Your right to refuse to be informed should also be respected.
- 5.4 You have the right to be informed and advised on all possible leisure activities, housing facilities and social care measures you could benefit from regardless of their cost. You should be able to decide which of these you can afford and you should be provided with all the information needed to make an informed decision.

Informed consent and advice

- 5.5 Your informed consent or that of the appropriate third person of your choice must be sought on decisions relating to all of your care and treatment, as well as to any participation in research projects and medical trials.
- 5.6 You have the right to legal advice, representation and defence. Legal aid should be made available if you lack sufficient resources.
- 5.7 Being spoken to openly, tactfully and in terms that you understand is part of your right to information and to giving informed consent.
- 5.8 You or a person of your choice are entitled to receive timely, clear and comprehensive information concerning all of the services that are available to you. This should include their respective costs, and options for adaptation to your needs.
- 5.9 Before concluding or amending an agreement or contract for services, you have the right to be fully informed and advised on the content and the possibility of making any future amendments to the agreement, including services and fees. Information about your rights and responsibilities should be clear and transparent.

Article 6

Right to continued communication, participation in society and cultural activity

If you depend on others for support and care you have the right to interact with others, and to participate in civic life, lifelong learning and cultural activity.

- 6.1 You should be made aware of and given opportunities to participate voluntarily in social life in accordance with your interests and abilities in the spirit of solidarity between generations. You also have the right to be given opportunities to perform paid or voluntary work and to take part in lifelong learning.
- 6.2 You should have access to support necessary to enable you to communicate. You are entitled to have your communication needs and expectations taken into consideration, in whatever way these are expressed.
- 6.3 You have the right to move freely to pursue your interests and activities. Should your mobility be impaired, you should have access to assistance in this respect.
- 6.4 You should have access to new technologies and to learning and support in how to use them.
- 6.5 You have the right to continue to exercise all of your civic rights, including the right to participate in political elections and should receive impartial assistance to do so if required. Your right to freedom of choice must be respected and confidentiality concerning your vote must be maintained by anyone assisting you.

Article 7

Right to freedom of expression and freedom of thought/conscience: beliefs, culture and religion

If you depend on others for support and care you continue to have the right to live according to your convictions, beliefs and values.

- 7.1 You have the right to respect for your values and beliefs, your philosophy of life and/or religious freedom regardless of whether or not these values are shared by those who are supporting you.
- 7.2 You have the right to practice and observe your religion or spiritual beliefs. You also have the right to obtain spiritual or religious care and guidance from representatives of your faith or spiritual beliefs when you wish. You have the right to refuse to participate in religious activity and to reject approaches by representatives of religions, faiths or philosophies of life.
- 7.3 Everyone, whatever their cultural heritage, religious values or practices has an equal right to respect and mutual tolerance.
- 7.4 You have the right to establish an association, join a group, and equally, the right to refuse to join.
- 7.5 You have the right to develop your political or social understanding and convictions and to widen your skills and knowledge in this respect.
- 7.6 You have the right to refuse any unwanted ideological, political or religious pressure, and you have the right to ask to be protected from this.

Right to palliative care and support, and respect and dignity in dying and in death

You have the right to die with dignity, in circumstances that accord with your wishes and within the limits of the law.

Article 8

- 8.1 You have the right to choose compassionate help and palliative care when you reach the end of your life and until you die and the right to choose measures to relieve pain and other distressing symptoms.
- 8.2 You have the right to expect that everything possible should be done to make the process of dying dignified and tolerable. Those treating and accompanying you at this time should respect your wishes and uphold them wherever possible.
- 8.3 You have the right to expect that the medical and care professionals involved in your end of life care should include and offer support to those close to you or other trusted persons, according to your wishes. Your right to exclude certain people should also be respected.
- 8.4 You have the right to determine whether and to what extent treatment, including life prolonging measures, should be initiated or continued. Your advance instructions should be respected if you are no longer assessed as being mentally competent.
- 8.5 Nobody may take any measures that would systematically lead to your death, except if they are authorized by your explicit instruction, or that of your legal representative, in accordance with legislation.
- 8.6 In the event that you are not able to express yourself, your advance instructions concerning decisions about your end-of-life care must be fulfilled, within the limits of legislation.
- 8.7 You have the right to respect for and observance of your religious beliefs and any wishes expressed during your lifetime about the arrangements for care and treatment of your body after your death.

Article 9

Right to redress

If you depend on others for support and care, you have the right to redress in case of mistreatment, abuse or neglect.

- 9.1 You have the right to support or to refuse support whenever you find yourself in a situation of abuse or mistreatment.
- 9.2 You are entitled to expect care professionals to be trained to recognize signs of abuse and mistreatment and act appropriately in order to safeguard you from any further mistreatment.
- 9.3 You have the right to be informed of the channels through which you can report abuse. You have the right to report abuse or mistreatment without fear of any negative repercussions, and to expect that the authorities will respond appropriately when you make a report. This right extends to those around you, particularly people who are responsible for your care and support.
- 9.4 You have the right to expect to be protected from the alleged situation of abuse or mistreatment when you file a complaint until the case has been fully investigated; this should not require a change of residence if this is against your wishes.
- 9.5 You have the right to access treatment to enable you to make a full recovery from any physical or psychological trauma you might have suffered as a result of abuse or mistreatment. You must be given time to recover at your own pace.

Your responsibilities

If you depend on others for support and care, you should:

Article 10

- 10.1 Respect the rights and needs of other people living and working within your environment and respect the general interests of the community in which you live; your rights and freedoms should be only limited by the need to respect similar rights of other members of the community.
- 10.2 Respect the rights of carers and staff to be treated with dignity, civility and work in an environment free from harassment and abuse.
- 10.3 You should seek respite care solutions in order to allow those giving you daily assistance the breaks they need to maintain their own quality of life and to enhance the quality of care they provide to you.
- 10.4 Plan for your future and take responsibility for the impact of your action or lack of action on your carers and relatives. This includes:
 - 10.3.1 Financially plan for long term care costs, both the known and unknown. You and your family have a responsibility to fund or contribute to the costs of your care to the best of your ability in accordance with your estate and your family's means.
 - 10.3.2 Establishing an appropriate third-party through an Enduring Power of Attorney to take decisions and advocate on your behalf when required.
 - 10.3.3 Leaving advance instructions detailing your choices regarding your health and welfare including care and treatment during your lifetime and at the end of your life as well as arrangements for your property and financial affairs. If you are unable to do so, it is the duty of your next of kin or your appointed representative to take decisions on your behalf, respecting your wishes wherever possible.
- 10.5 Inform the relevant authorities and those around you about a situation of abuse, mistreatment or neglect that you experience or witness.

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On behalf of Bermuda's Seniors

Appendix. Resources used for Charter Development

European Charter of the rights and responsibilities of older people in need of long term care and assistance
The Charter of fundamental rights of EU
Human Rights Act 1981
Recommendations for a National Policy on Disabilities, Ministry of Health, Government of Bermuda 2010
Bermuda Health Strategy 2014.2019
Residential Care Homes and Nursing Homes Act 1999, Regulations 2001 and Code of Practice for Care Homes 2018
Senior Abuse Registrar Act 2008
Mental Health Act 1968
Power of Attorney Act 1944
Criminal Code Act 1907
Standards of Practice for Nurses and Nursing Associates – Bermuda Nursing Council
Standards of Practice for Medical Practitioners – Bermuda Medical Council

