End of Life Assistance (Scotland) Bill
Royal College of Speech and Language Therapists

Introduction

The Royal College of Speech and Language Therapists (RCSLT) is the professional body for speech and language therapists (SLTs) and support workers. RCSLT acts to promote and protect the interests of both its members (1000 of whom work in Scotland) and speech and language therapy service users.

RCSLT does not support or oppose the passing of this Bill. Our interest stems from situations in which;

• the person seeking to end their life has a speech, language or communication issue which may impact on their ability to communicate their preferences or consent effectively. This may include a person with aphasia but NOT dementia or other degenerative mental condition (who are specifically excluded in the Bill) Speech, language and communication difficulties are a feature of a range of conditions some people may find “intolerable”, for example severe stroke, head and neck injury, or progressive diseases such as Parkinson’s.

and / or

• SLTs are members of the team providing care to someone with a communication or swallowing issue related to the terminal illness, for example someone with head & neck cancer or who is “permanently physically incapacitated” by stroke or physical trauma.

RCSLT are keen to represent the needs (as RCSLT interpret them) of those with speech, language and communication needs in both exercising choice and being kept safe. We are also keen to represent the professional opinions of our members, who have a variety of views and concerns about the Bill.

This response is composed of the views of expert SLTs in relevant areas (e.g. palliative care, stroke, traumatic brain injury) and other members. The contribution of the RCSLT Palliative Care special interest group has been extensive and crucial.

Comments and recommendations

a. Ensuring equal rights for those with communication support needs

Although communication difficulties (with no cognitive impairment) are not uncommon among those conditions which may prompt someone to believe their life is “intolerable” there is no relevant reference to or example of people with speech, language and communication needs in the Bill.
RCSLT would wish to the Committee to consider the need to ensure people with communication difficulties but no “mental conditions” impairing capacity would not be excluded from the opportunity and/or protections (from pressure) afforded by the Bill by virtue of their communication support needs. Further RCSLT would hope that assertion of choice through use of an augmentative or alternative communication device, (AAC) as opposed to strictly verbal or written consent could be recognised as valid and reliable expression of will.

b. Ensuring adequate Communication Support for those exercising their rights under an EoLA Act
Assuming people with communication difficulties were, within the framework of an Act, ensured equal rights to choose (and be protected from) assisted end of life RCSLT would wish the Committee to consider ensuring the communication supports available to such people were adequate throughout the necessary process.

RCSLT would recommend, for instance, that an adequately qualified SLT should be involved to

- assess and individuals level of comprehension and hence ability to make a complex decision around assisted dying and its consequences
- support individuals with severe but cognitively unimpaired expressive language difficulties the individual to express their wishes reliably using appropriate augmentative or alternative communication systems

The Committee should note that at present, although SLTs often facilitate communication with the groups of people affected by this Bill very few have

- the specific skills to manage the process outlined in the Bill,
- currently work in or have knowledge of specialist palliative care team or
- have the professional support to discuss such cases

Implementation of the Bill / Act would therefore have resource implications for training, support and supervision for the profession not least in the legal implications for an SLT acting under the Act.

c. Range of conditions covered by the Bill
RCSLT believes the term ‘degenerative mental conditions’ needs clarification.

RCSLT are concerned that groups such as those people with Multiple Sclerosis or Motor Neurone Disease (which may at some point in the course of the disease involve some degree of cognitive impairment) will be excluded from the Bill. Consideration should be given to the question of at which point in a degenerative condition should a person be given the opportunity to exercise their rights under the Bill / Act?

d. “Designated Practitioners”
Medical practitioners are not necessarily expert at assessing or enabling communication by people with communication support needs.
Linked directly to the point above regarding ensuring adequate communication support RCSLT believes the Bill should recognise the full range of professionals involved in caring for those who may be affected by the Bill. In particular RCSLT would wish people with communication difficulties are given access to the skills and role of the speech and language therapist within the multi-disciplinary team. This would assist the designated practitioner, for example, to reliably and adequately implement Section 9, Part 4 C (“communicating such a decision”).

e. Opting out for individual professionals.
RCSLT would recommend that appropriate protections are in place for all professionals who have a cultural, religious or moral objection to involvement in the procedures associated with the Bill.

f. Cultural Issues
Cultural issues have not been addressed in the bill. These issues need to be carefully considered within a multi-racial/multi-cultural society, and all professionals would need to be very aware of people’s specific cultural issues relating to assisted dying.

g. Access to alternatives
Currently, there is inequality of access to good quality palliative care.

People with communication support needs in those areas where services are not so well developed may not feel that palliative care is an option for them (including more open access to hospice/specialist community palliative care.)

Some of the individuals considering assisted dying may be those who are currently not receiving a service comparable to cancer sufferers e.g. people with motor neurone disease.

RCSLT would wish the Bill to ensure people were given equal and quality access to alternatives to assisted end of life as part of the process of decision making.

Kim Hartley
RCSLT Scotland Policy Officer