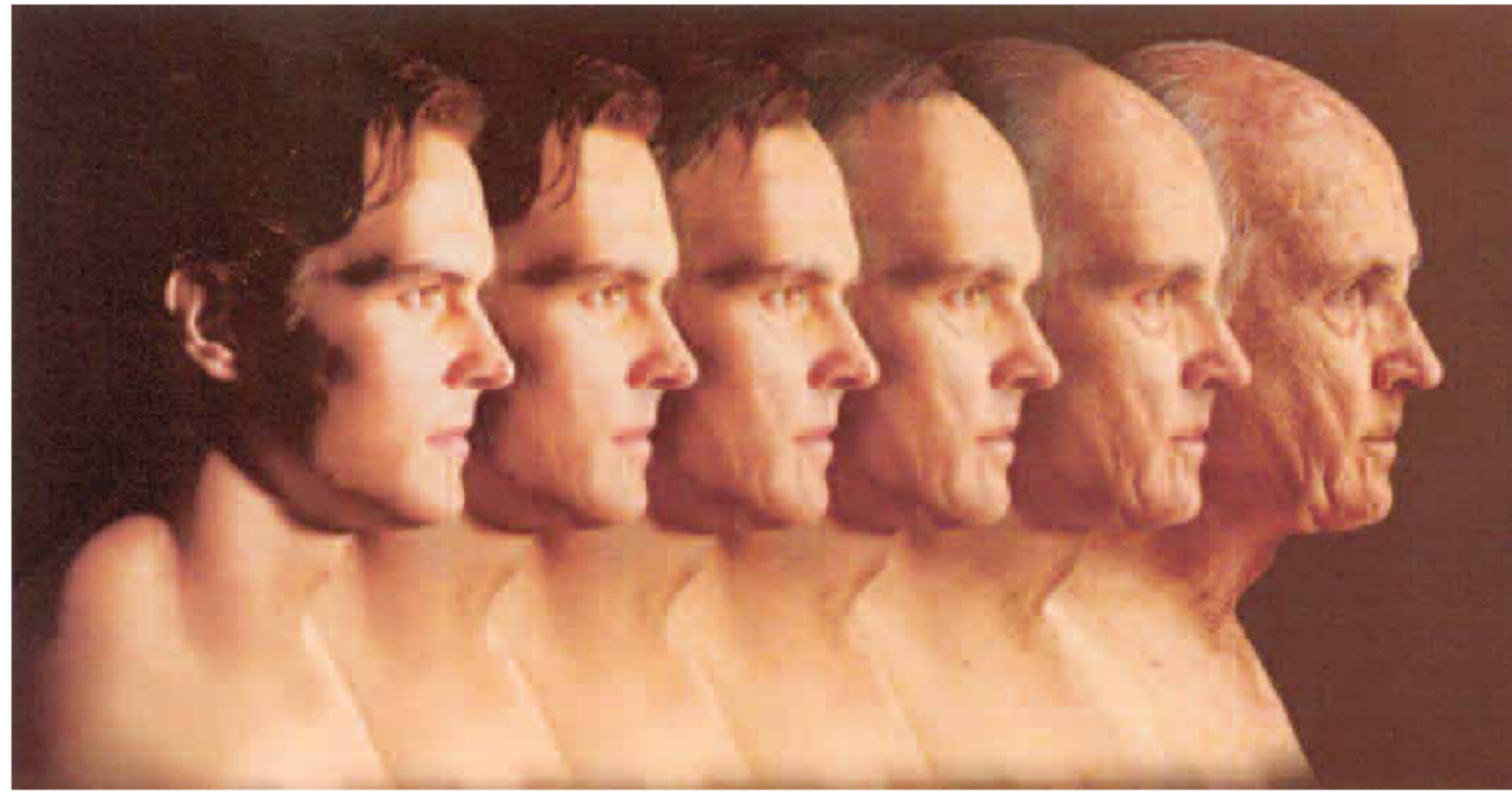


INTEGRATING AGEING WITH A BLEEDING DISORDER INTO CANADIAN HEMOPHILIA SOCIETY STRATEGIES

C. Cecchini, D. Page, Canadian Hemophilia Society



Canadian Hemophilia Society
Help Stop the Bleeding
Société canadienne de l'hémophilie
Arrêtons l'hémorragie



Issue

Today, a person with a severe bleeding disorder who has access to advanced care has almost the same life expectancy as someone unaffected. This positive news, however, is accompanied by the increased incidence of ageing illnesses complicated by the underlying bleeding disorder. Since 2010, the Canadian Hemophilia Society (CHS) has undertaken a variety of strategies to identify needs and to develop programs to optimize quality of life of people with bleeding disorders as they age.

Methodology

In 2010, a multidisciplinary working group on ageing composed of HTC health care providers and patients was established. A survey of Canadian HTC health care providers was conducted to determine the information and support needs of health care providers within and outside the HTC setting in dealing with the age-related health complications of people with bleeding disorders.

In 2011, the topic "hemophilia and ageing" became a centre piece of the biennial CHS Medical and Scientific Symposium. Speakers and topics included:

- *The ageing haemophilic population: a major success and a major challenge*—Dr. Gerard Dolan, UK
- *When you only have 100 years to live: A Canadian perspective on aging*—Dr. Karen Fruetel, Canada

Focus group methodologies were then used to enable patients from across Canada to share personal experiences of ageing with a bleeding disorder; identify needs and challenges; and make recommendations for CHS program initiatives to optimize quality of life amid ageing processes.

ISSUES RAISED:

Should continuous infusion be considered as a hemophilic ages?

Is a new approach to colonoscopy needed?

How can risk of osteoporosis be reduced?

Heart, kidney and prostate condition issues

Pain management

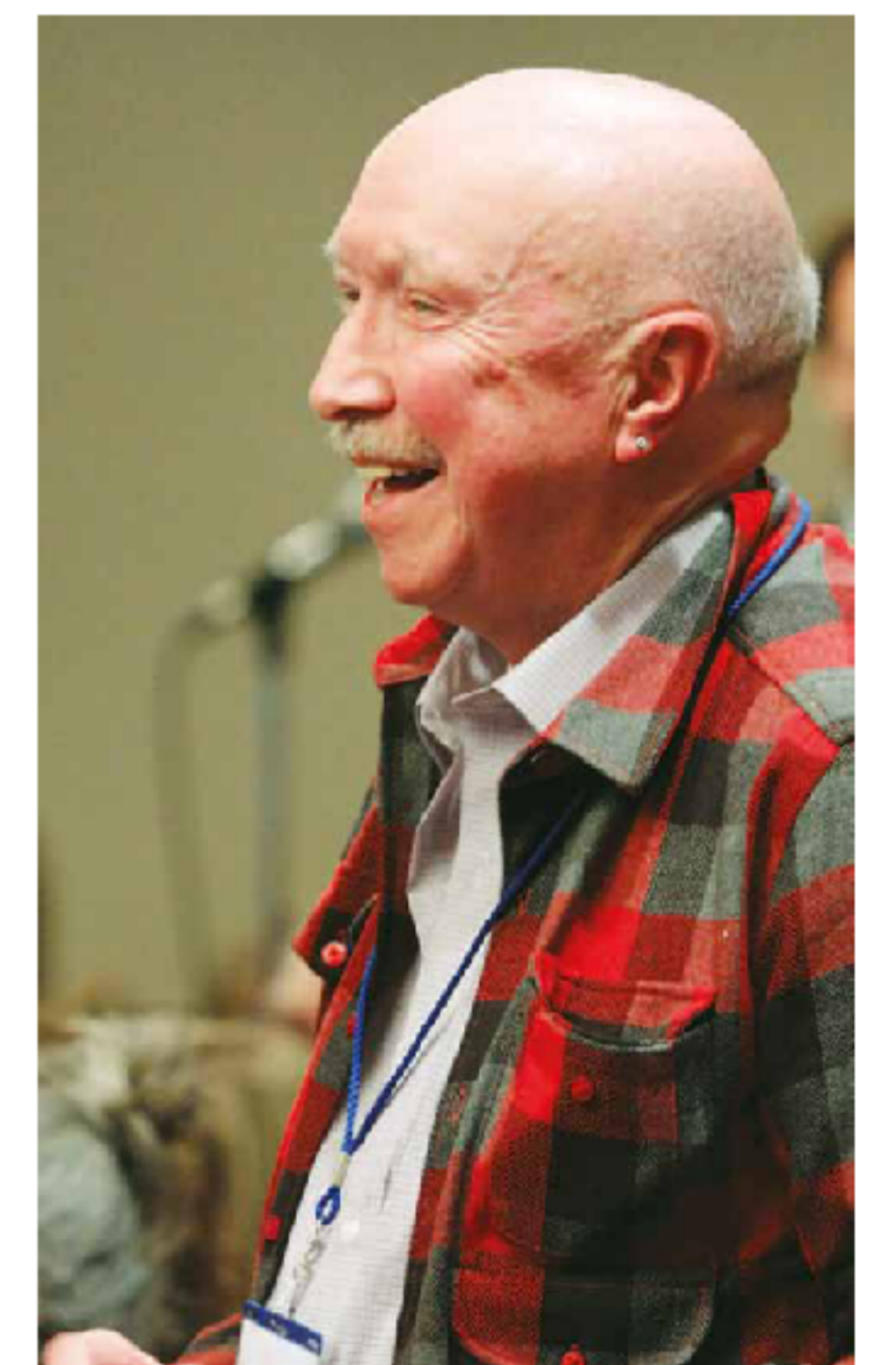
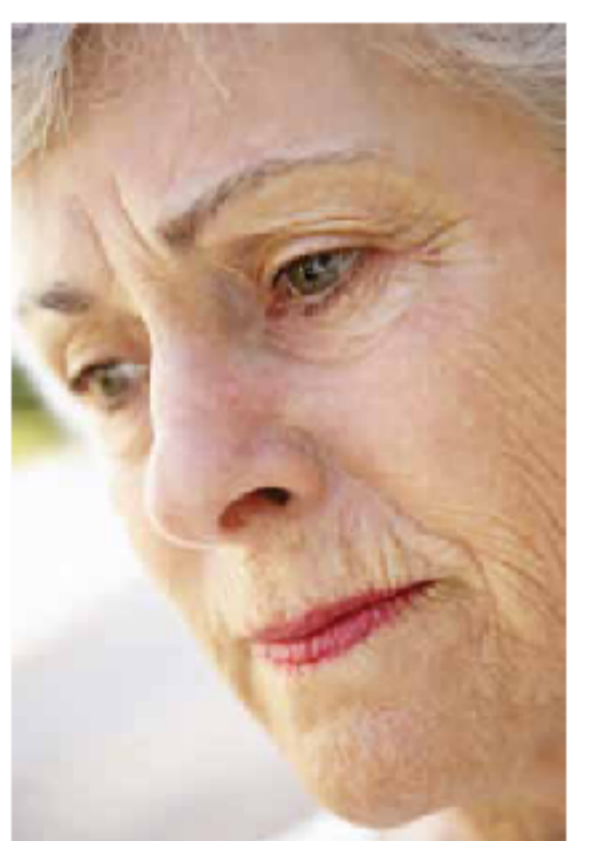
Increased fragility including heightened possibility of falls

Will nursing home staff have the knowledge, experience and sense of caring to watch out for us in case of a bleed?

How do we implement an increased emphasis on physical fitness to improve quality of life in older age?

The need for and involvement of an even broader range of medical specialties

An increase in mobility limitations

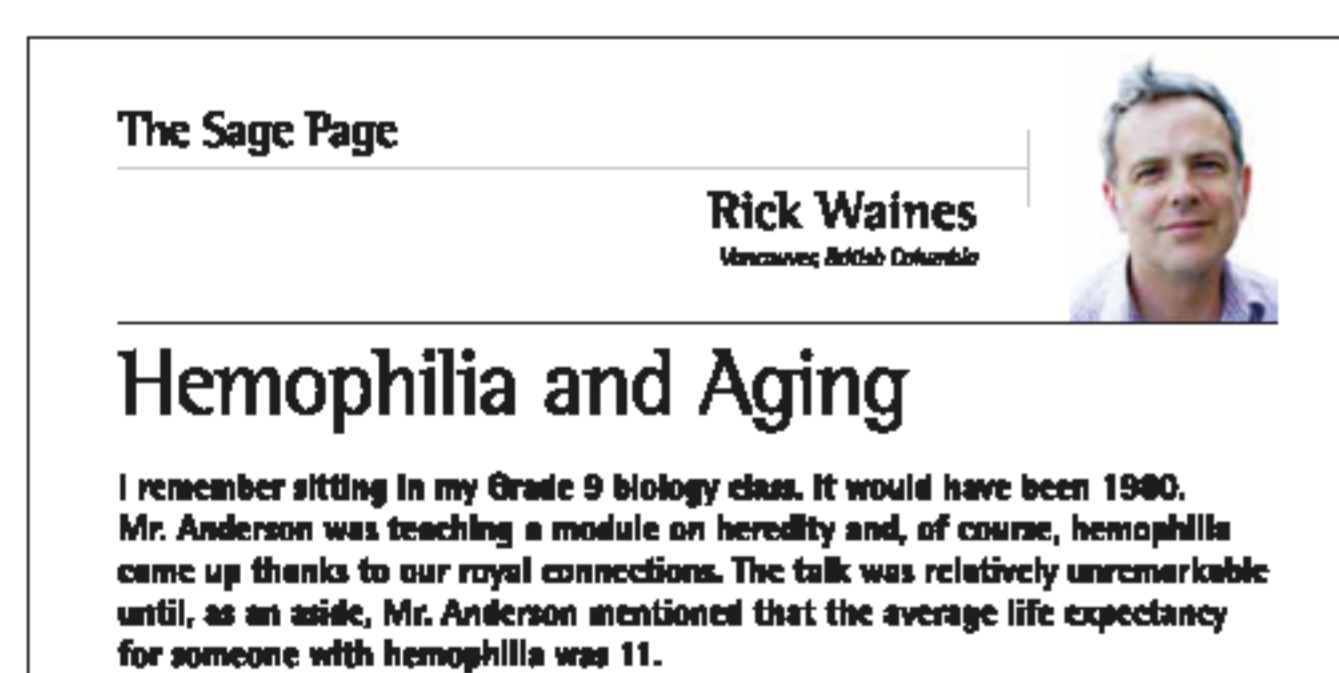


Outcomes

Feedback from the focus group indicated that educating patients, family members and health care providers both within and outside of the HTC was a priority. As a result of the focus group recommendations, the following initiatives have been undertaken by the CHS:

- A new column on ageing, *The Sage Page*, is now featured in the CHS newsmagazine, *Hemophilia Today*.
- A first appointment wallet card, *Partners in Care*, was developed encouraging specialists and other medical professionals to contact HTCs before undertaking invasive procedures.
- The model for a regional workshop on ageing is being piloted in Ontario and will eventually be implemented across Canada.
- The model for a specialized multidisciplinary clinic for 40-plus patients has been piloted at the British Columbia HTC.
- A new section on ageing with a bleeding disorder will be created on the CHS Web site.

It is hoped that these and future strategies will optimize the quality of life of people with bleeding disorders in Canada as they age.



Partners in Care | THIS PATIENT HAS A BLEEDING DISORDER THAT MAY COMPLICATE THERAPIES AND PROCEDURES.

If you can safely do so without risk to the patient, please contact the patient's bleeding disorder treatment centre indicated on the reverse side of this card prior to:

- ▶ undertaking any invasive procedure or surgery such as: biopsies | cardiac procedures – e.g. valves/stents | arterial punctures or IM injections | colonoscopy | dental surgery
- ▶ prescribing ASA, NSAIDS, anticoagulant or antiplatelet therapy
- ▶ determining plans for perinatal care

Canadian Hemophilia Society
www.hemophilia.ca

AHDC
Association of Hemophilia Clinic Directors of Canada

NAME OF PATIENT: _____
DIAGNOSIS: (Please refer to the patient's Factor/Inhibitor or Test/First card) _____
BLEEDING DISORDER TREATMENT CENTRE: _____
HOSPITAL: _____
PHYSICIAN: _____
NURSE: _____
TELEPHONE: _____

