### The changing face of HIV: Mildmay UK responding to HIV-related neurocognitive impairment / Mildmay, transforming HIV care.

#### **Contributors**

Mildmay UK

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# The changing face of HIV





Mildmay UK

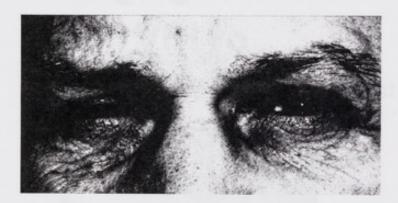
Responding to HIV-related neurocognitive impairment

### Mildmay UK

## Europe's only specialist HIV-related neurocognitive rehabilitation unit

#### What is HNCI?

HIV-related neurocognitive impairment (HNCI) is the name given to a wide range of symptoms that affect the ability of a person living with HIV to function in their everyday life.



#### What causes HNCI?

It can be caused by the direct impact of HIV on the brain or by 'opportunistic' infections (infections that can occur when people have a weakened immune system)

HNCI is usually found in those with high viral load and/or a low CD4 T-cell count (two measures used to indicate the progression of HIV) and typically in those who have been living with HIV for an extended period or have been diagnosed late.

HNCI can be both prevented and treated through a combination of antiretroviral drugs. In order to be effective, it is necessary to take all the doses of the drugs as prescribed. It is often those people who either haven't ever taken antiretroviral drugs, or who haven't been able to take them as prescribed, that begin showing the symptoms of HNCI.

#### What are the symptoms?

The symptoms of HNCI can vary massively from person to person. They can include:

- · confusion and disorientation
- · lack of coordination, clumsiness,
- unsteadiness and mobility problems
- loss of daily living skills (e.g. the ability to dress yourself or make a cup of tea)
- · depression, mood swings and
- · uncharacteristic behaviours
- speech and language difficulties
- · loss of short-term memory
- difficulty in evaluating risk and danger
- frustration and concentration problems
- · loss of 'self'
- inability to make decisions

Many of these symptoms can affect a person's ability to take care of themselves, and also make it very difficult for them to take their medication correctly. This, in turn, can compound the problems of HNCI, causing a vicious circle.



#### What can be done?

Although there is no cure for HIV, recovery or partial recovery from HNCI is possible.

Mildmay UK currently runs Europe's only specialist HNCI rehabilitation unit. The centre combines cutting edge medical and nursing care with a wide range of rehabilitative therapies in a holistic model.

Mildmay UK's unique service includes counselling, occupational therapy, dietetics, physiotherapy, speech and language therapies and mental health support to address the complex needs of people living with HNCI.

Alongside our programme of rehabilitation, and the multidisciplinary approach to restoring social skills, we provide a supervised adherence programme that reflects the importance of sticking to antiretroviral medication regime for someone living with HNCI. This approach has proved highly effective, with 40 per cent of those admitted to our centre able to return to independent living.



Since opening Europe's first specialist AIDS hospice in 1988, Mildmay has always been at the forefront of pioneering HIV care. It was through its early work in palliative and end of life care that Mildmay began to see a need to develop services for people showing signs of HIV related brain impairment.

As medication and survival rates have improved, Mildmay UK's focus has shifted away from end of life care to a more structured programme of rehabilitation to help people with HIV-related cognitive impairment to relearn the skills they need to care for themselves.

#### Mildmay International

Mildmay International is a British charity specialising in HIV and AIDS care, training and service development in the UK, sub-Saharan Africa and other resource-limited settings.

Originally founded in 1866 to tackle the cholera epidemic in London's East End, Mildmay has been providing care for people living with HIV for more than 20 years.

In 1988, we responded quickly to the escalating crisis, opening Europe's first dedicated AIDS hospice in London. Mildmay International was soon called to extend its expertise to areas of the world worst affected by HIV and AIDS. We now have programmes in countries across sub-Saharan Africa and also work in Eastern Europe.

Our vision is of a world in which everyone with HIV can have life in all its fullness.

#### Mildmay UK

Today, Mildmay UK is Europe's only specialist rehabilitation centre for people with HNCI (HIV-related neurocognitive impairment). Our expertise in the field is recognised internationally.

Our unit in East London, currently offers in-patient care for 16 patients, day services for 60 clients providing programmes to help people continue living well in their own home and training and awareness-raising around HNCI.

Care is holistic and tailored to individuals, who often have very complex needs. Our rehabilitation programme aims to enable a person to live life to their maximum potential.

Mildmay UK also offers assessment and rehabilitation programmes for patients who are unwell and physically impaired due to HIV, targeted support programmes for those with significant problems in taking medication, and psychological support for those with mental health problems.



### For information about the clinical work of Mildmay UK contact us on:

T: 020 7613 6300

F: 020 7729 1896

E: simon.rackstraw@mildmay.org

### If you would like to support the work of Mildmay UK contact us on:

T: 020 7613 6311

F: 020 7613 6329

E: info@mildmay.org

Mildmay UK, Austin Street, London, E2 7NB www.mildmay.org

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