



Sussex Community
NHS Foundation Trust

HIV Nursing – The Early Years

*Competing interest
disclosure – None
declared*

Anna Bamford
Clinical Service Manager HIV
Community HIV Specialist Service



Excellent care at the heart of the community





The Terrence Higgins Trust

The Terrence Higgins Trust

A Registered Charity To Inform, Advise And Help on AIDS, ARC and HIV.

82-84 GRAYS INN ROAD LONDON WC1X 8JH

ADMINISTRATION 01-851 6530 HELPLINE 01-242 1818 VISTEL 01-406 2483

Our ref: Gen

Anna Barnford
Flat Two
71 Queens Road
Twickenham
Middlesex TW1 4EU

27th July 1989

Dear Anna,

Thank you all for raising the magnificent sum of £175.00 for the Terrence Higgins Trust.

We are all Living with AIDS and Living with AIDS means being there - for our friends, for each other and for ourselves. That THT is committed to changing the climate of fear, misinformation and prejudice that still surrounds this health crisis. We are committed to sharing our knowledge and expertise with all who work in this area of care and health education, to providing information and advice on HIV/AIDS and most important of all, to work with and meet the very real and practical needs of all people with AIDS and those who support and love them.

Sadly, there is no end to this health crisis in sight. The calls for our services increase weekly and our organisation is growing rapidly to meet this demand. Your generous support has not only contributed financially to provide these services but also encourages and boosts morale in an extremely difficult and distressing area of care and concern and for this we thank you.

With all Good Wishes,

Yours sincerely,

Liz Davies

Liz Davies
FUND RAISER



29th October 1996

Anna Banford
Clinical Sister
Wilnot Ward
Ealing Hospital NHS Trust
Uxbridge Road
SOUTHALL
Middlesex UB1 3HW



Dear Ms Banford

FASHION ACTS is the British Fashion industry's initiative to raise money for people affected by HIV and AIDS. It was set up in 1988 and so far has raised approximately £1,000,000.

Each year **FASHION ACTS** gives presents to people hospitalised over the Christmas period. Last year we visited 14 hospitals and gave gift parcels to over 240 patients, this included the Wilnot ward and we would like to do so again this Christmas.

I would be most grateful if you could let me know if this is acceptable to you and if so please supply me with the expected patient numbers - men, women and families, and when it would be convenient for us to deliver. We are hoping to deliver the presents on Christmas Eve.

Please contact me at 18 Pembroke Mews, London, W8 6ER or phone 0171 938 2323.

I look forward to hearing from you.

Yours sincerely

Amy Li

AMY LI
TRUSTEE

The fashion industry's
initiative to help people
affected by HIV/AIDS

Fashion Acts Ltd
30 Elgin Crescent
London W11 2JR
Tel: 0171 229 7348
Fax: 0171 221 8795

Trustees
Sally Brampton
Beverley Cable
Amy Li
Stewart Mechem
Terence Nelder
Martin Raymond
Andrew Wiles

Co-Ordinator
Kathy Davies

*as/n sent letter - asked
for presents for:
9 - men
4 - women*

Company secretary:
Elaine Burgess

Reg. Office
12-36 Great Portland Street
London W1N 5AD
Reg. Charity No. 1048767
Company No. 3074279



fashion acts





Programme

ENB
Course
934

*The Care & Management of
People with HIV Disease*

*Riverside College
of Nursing*

*Faculty of Continuing
Education*

at

The Royal Masonic Hosiptal

January 1990 –
15 days course (not
including pre- and post-
course study days)

Topics included:

- The Evolution of an Epidemic
- Death and Dying
- Women's perspectives on AIDS
- Injecting substance misuse
- Bio-medical ethics

Afternoon Programme *25th May 1994*

13.45-16.30

Concurrent sessions:

Concurrent sessions will run as follows:

Session 1:- 13.45 - 14.30

Session 2:- 14.40 - 15.25

Session 3:- 15.45 - 16.30

Long Term Drug Therapies
(Venue- Conference Room)

Roger Newham

Living Wills
(Venue- Meeting Room)

Peter Watt

Funeral Arrangements
(Venue-Meeting Room)

Melanie Dobbin

Effective Control of Pain
(Venue-Resource Room)

Kate Golton

Complex Care Assessment
(Venue- David Powells Office)

Kath McClinton
& Susan Bowman

Community Liaison
(Venue-TBA)

Johnny Deighan

16.30-17.00

Evaluation & Close

Steve Lemox

Speakers

Sian Edwards,
Clinical Nurse Lecturer,
Riverside College of Health Studies.

Kath McClinton,
Senior Social Worker,
Chelsea & Westminster Hospital.

Anna Bamford,
Senior Staff Nurse,
Chelsea & Westminster Hospital.

Susan Bowman,
Social Worker,
Chelsea & Westminster Hospital.

Eileen Nixon,
Sister, Kobler Centre,
St Stephen's Clinic,
Chelsea & Westminster Hospital.

Roger Newham,
Team Leader,
Chelsea & Westminster Hospital.

Peter Watt,
Lecturer,
Riverside College of Health Studies.

Melanie Dobbin,
Charge Nurse,
Chelsea & Westminster Hospital.

Kate Golton,
Palliative Care Nurse Specialist,
Chelsea & Westminster Hospital.

Johnny Deighan,
Charge Nurse, Community Liaison Team,
St Stephen's Clinic.

CLINICAL HIV UPDATE FOR NURSES

C H E L S E A
— & —
W E S T M I N S T E R
Healthcare

(5) HIV Disease as a Long Term Chronic Illness?

25th May 1994

9.00 - 17.00hrs

Programme

*Venue- Conference Room, 4th Floor, St Stephen's Clinic,
Chelsea & Westminster Hospital.*

8.30 - 9.00

Registration & Coffee

***Wilmot
Ward***



***Cameron
Centre***

*Dr Stephen Ash and team
request the pleasure of your company at
the official opening of
'Wilmot Ward' and 'Cameron Centre'
by
Sir Ian McKellen
on Tuesday 1st November 1994 at 2.00pm*

R.S.V.P
081-967 5551
The Pasteur Suite
Ealing Hospital
Uxbridge Road
Southall, Middx UB1 3HW



Sir Ian cuts the ribbon

STONEWALL founder Sir Ian McKellen visited Ealing Hospital on Tuesday to open a new HIV/ AIDS ward, laboratory, education and administration unit. The nine-bed Wilmot Ward has been named after a former patient, as have the other facilities — now known as the Cameron Centre. Pictured with McKellen is consultant Dr Stephen Ash.

PHOTO: GORDON RAINSFORD



Celebration as Aids unit is declared open

ACTOR and gay rights campaigner Sir Ian McKellen was joined by 130 guests including staff and managers when he opened the new specialist HIV and Aids ward at Ealing Hospital on Tuesday. The new ward was named after Bede Wilmot, a local teacher who contracted Aids and worked with pupils on dispelling some of the myths surrounding the disease. Mr Wilmot's partner, Tony Phelan, and some of his relatives also attended the opening of the £777,000, nine-bed ward. The new addition means the hospital is now the best equipped community hospital in the country for with HIV and Aids. Also being opened was the Cameron Centre for Aids victims. The new unit will be a...



Knight opens new centre for HIV sufferers

TOP British actor and gay-rights campaigner Sir Ian McKellen opened a new HIV and AIDS centre at Ealing Hospital last week.

The Cameron Centre, including the nine-bed Wilmot Ward, a laboratory and an education unit, has been named after former patients.

Sir Ian said: "I'm sorry I hadn't been asked to close this ward rather than open it."

"I wish someone had found a vaccine so facilities like this with someone who were no longer required."

Ealing now boast the largest HIV and AIDS unit in any community hospital in the country. In 1990 the Pasteur Suite was opened to provide outpatient facilities for HIV and AIDS sufferers. Since then the number of HIV and AIDS patients treated at the hospital, on Uxbridge Road, has increased by 10 times to 200.

The hospital's Pasteur Suite Appeal has raised £18,000 by 10 times to 200. The hospital's Pasteur Suite Appeal has raised £18,000 by 10 times to 200. The hospital's Pasteur Suite Appeal has raised £18,000 by 10 times to 200.



SEE THIS: An official shows off a





PICCs *in HIV*

Many nurses are realising the benefits of PICCs to their patients in areas such as oncology and nutrition. However, the move into areas such as HIV has not been as rapid.

Since attending a Bard Groshong PICC workshop about a year ago, we have been successfully using PICCs in HIV patients for administering treatment lasting anything from 2 weeks to several months. This can range from a course of antibiotics, drugs such as foscarnet and gancyclovir, and for taking blood.

PICCs are an extremely cost-effective, safe device to use in HIV treatment, with

infection rates kept much lower than subclavian lines.

They are very well received by our patients in relation to body image. Patients have often requested to have a PICC placed in preference to other VADs as they are more aesthetic. The main complication we have found with PICCs is the incidence of mechanical phlebitis. We have reduced the incidence of this by heating the arms, keeping the veins warm and therefore dilating them. However out of the 30 PICCs we have placed over the last year, we have come across very few complications.

The use of PICCs in HIV is a nurse-led initiative which has resulted in a direct improvement in the quality of holistic patient care.



Christine Green, Senior Sister, Anna Bramford, Clinical Sister, Ealing Hospital NHS Trust



What is sexual health?

Facts

NEW guidance for schools on sex and relationship education was issued in July 2000

BEST practice guidance has been issued on effective contraception and advice services

PRESS release (29 November 2001) HIV showing no sign of decline, while gonorrhoea, chlamydia and syphilis have doubled in five years

NUMBERS of heterosexually acquired HIV infections diagnosed in the UK have risen steadily over the last 15 years and since 1999 have been greater than the number acquired through sex between men. The total of new diagnoses of HIV in those infected heterosexually is expected to rise to over 1500 for 1999.

- Sexual health needs of vulnerable groups including women in prison and people with learning disabilities
- Guidance for sexual health nurses on the implications of the Crown Report on prescribing and administration of medicines
- HIV service developments, including the needs of long-term survivors living with HIV/AIDS with treatment
- Erectile dysfunction

For more information contact
RCN Sexual Health Forum on 020 7409 3333

Royal College of Nursing

SEXUAL HEALTH AND HIV SERVICES

LEARNING OBJECTIVES

- To review key implementation challenges and progress in implementing the National Strategy
- To explore the effective commissioning toolkit for sexual health and HIV Services
- To highlight good practice in the integration of HIV/AIDs services
- To share innovative approaches in service commissioning
- To highlight good practice in partnership working

IMPROVING COMMISSIONING AND DELIVERY

Keynote Speakers:

CATHY HAMLYN

HEAD OF SEXUAL HEALTH & SUBSTANCE
MISUSE, DEPARTMENT OF HEALTH

JANE MEZZONE

SEXUAL HEALTH PROGRAMME MANAGER
DEPARTMENT OF HEALTH



H A R R O G A T E
CENTRE FOR EXCELLENCE
IN HEALTH & SOCIAL CARE

A ONE DAY CONFERENCE

Tuesday 29 April 2003

CENTRAL LONDON





Anna in America

Anna Bamford, manager of the community HIV team, was the only nurse from England among the 700 delegates at the annual conference for nurses in AIDS care, held in New Orleans.

Anna heads the integrated HIV team which offers nursing, mental health and social care support from its base at the Old Market in Hove.

"Many of the nurses I met were interested in the fact that our community specialist team is an integrated service and supports the majority of patients in their own homes," she said.

"Overall, the conference revealed the latest progress in treatments, current approaches to care, ethical and social issues surrounding HIV and AIDS, and ways for nurses to support each other.

"I also took the opportunity of visiting a local HIV out-patient clinic which has 3,500 patients on its books."

Other aspects of HIV care covered during the conference included medication and side effects, HIV pregnant women, nutrition and HIV prevention.

For more information, contact Anna on 267575.



Anna Bamford, manager of the community HIV team, was the only nurse from England among the 700 delegates at the annual conference for nurses in AIDS care, held in New Orleans.

A Decade of Change

A Bamford, S Mirfin, C Bellingham

Objective

There are three Community HIV nurses in Brighton, who collectively have 45 years HIV nursing experience, we have looked back, and reflected at the changes in HIV care for patients over the last decade. This has been inspired by the tenth anniversary of the BHIVA conference.

The main objective of the study was for the nurses to reflect upon their clinical practice, experience and patient's stories over the last 10 years and to inform us of potential areas we may develop as nurses and services.

Methods

The methodology used was a reflection on practice and sharing of patient stories over the last 10 years of nursing. Three main areas affecting patients were: physical, psychological and social needs from 1998-2008 and how they have changed for the both the patient, nurses and service providers.

Results

The three main themes explored have shown significant changes in nursing practice, patients physical health needs around their HIV and how this has evolved from a palliative and terminal care approach to a chronic disease model of care.

This in turn has led nurses to acquire new skills in Chronic Disease Management, to keep abreast of the constant changes in Antiretroviral medication and its management, to increase their knowledge of HIV and co-morbidities and to deal with the continual impact of new diagnosis and the complexities of patients who present late.

Patients psychological and mental health needs have also changed with an increase in chronic depression, anxiety issues, adjustment disorders, isolation and low self esteem. The social care needs for people in 2008 are significantly different including housing, returning to work, and the most significant locally is the increase in asylum patients and cultural issues.

1998

2008

Mental Health

- AIDS dementia
- Progressive multifocal leukoencephalopathy
- Adjustment disorders (pre and post test results)
- Life span changes
- Depression
- Counselling
- Stigma & discrimination
- Isolation

Physical Health

- Complex Antiretroviral regime (food & fluid restrictions)
- Lipodystrophy & its psychological effects
- Kaposi's Carcinoma
- Cytomegalovirus
- Aids related
- "Start early-hiv hard" approach to medication
- Limited resources for monitoring treatment and adherence (CD4 & Viral Load)
- Peripheral Neuropathy
- Increase in HIV C
- Increase in drug trials
- Early use of Post Exposure Prophylaxis

Social Issues

- Concerns around mortgage & insurance
- Large voluntary input (SARF)
- London Lymphatic residential care costs
- Increase use of HIV support bath
- Emerging changes of patient demographics
- Regular use of CD4/CD8 - linked life expectancy
- Limited General Practitioner involvement
- HIV are stop shop (we did it all)
- Profile of HIV still raised across media
- King David money - AIDS Support Grant
- Stigma & discrimination
- Confidentiality challenges

Conclusion

The result of this study showed that we cannot clearly forecast the next 10 years of HIV, however we can say with some confidence that it will be another period of significant change. HIV nurses have always been creative, flexible and open to change by continually increasing our knowledge base, experience and skills. Partnership working has evolved. But the ongoing reduction of funding and changing government agendas over the years has meant we now need to be transparent about the outcomes of interventions and continually re-evaluate our services to meet the needs of our patients.

Mental Health

- Ongoing stigma & discrimination issues
- Depression
- Suicide
- Mental Capacity Act
- Personality Disorders
- Dementia
- Anxiety
- Psychological distress living with uncertainty
- Isolation

Physical Health

- Cancer
- Co-infections - Hepatitis C
- Multiple Drug Resistance
- Chronic Disease Management
- Late Presenters - Kaposi's Sarcoma, PCP
- Complex health problems (Endocrine, Gastrointestinal, Cardiac)
- People Living Longer - implications of ageing
- Increase in Sexually Transmitted Diseases (Syphilis)
- Women having sex children
- Simplified drug regimes
- CD4 & CD8
- Health Promotion around smoking, drinking, drugs, sex, diet, weight loss
- Access to rapid HIV tests
- Routine use of Post Exposure Prophylaxis

Social Issues

- Criminalisation of HIV
- Increase of Black & Ethnic Minorities
- Asylum Cases
- Benefit Reviews
- Increased access to mortgages and insurance
- Increase in GP involvement (HIVed counsel)
- Increase of cost for ARV's - impact on high income
- Decrease of voluntary sector
- Concerns around confidentiality (IT systems)
- TSO concerns around travelling restrictions
- Increase awareness of cultural issues

What next for the future...

- Self-management - HIV patients have complex needs that require a holistic approach. Equal attention is needed to physical, psychological, emotional, and social needs.
- Patients should have more choice & control over their care. Provide baseline assessments and individual care plans with agreed outcomes.
- Tackle complexity - raise the profile of your service.
- Constant changes for professionals & patients, need to work together in partnership.
- Increase the use of BHIVA components to support HIV nurses through their development.
- Increase your awareness of the impact of health inequalities and how the needs and rights of minority groups can be protected, maintained and supported.
- Encourage service user feedback to inform development of services, e.g. possible use of telephone/web services/extended access.

So in conclusion - where could HIV nursing be in 2018?

References

1. UK Department of Health. *Healthy 2008: High Level Challenge for Health and Social Care*
2. International Health 2008. *Our Law, Our Health, Our World*. The World Health Organization

A Decade of Change

**HIV
Nurses
are
great!**



**Here's to
the next
generation!**