Tenth Progress Report of the College of Medicine Home Based Care Project – December 2013

Introduction

This is the tenth report of the College of Medicine Home Based Care Project - a project financially supported by UK Charity, the Malawi Home Based Care Charitable Trust. This report is for people and organisations that have made donations to the Trust in the past and provides details of activities, financial information and outlines future plans of the project. On behalf of everyone involved in the project, we thank you for your support of the Malawi Home Based Care Charitable Trust to date and hope you feel able to continue to support us.

Background

The College of Medicine Home Based Care Project was established in 2005 with the primary aim of relieving pain and suffering of people living with chronic illness, usually HIV/AIDS, in the poorest two townships of Bangwe and Limbe in Blantrye, Malawi. Currently the project has a dedicated team of 2 trained nurses (one of which is also the project manager), 5 home based care assistants and approximately 150 community volunteers. Initially volunteers visit members of the community who they have heard are critically ill. They refer those that they feel are in need of home based and palliative care to the



nurses. A nurse and home based care assistant make a visit and assess the patient's needs. Together the team provide patients with basic nursing care, counselling, medication and pain relief and support and advice for the patients' carers. The team carry out approximately 600 home visits of new and old patients per month.

In addition, the project manages:

- A 'positive living' support group for people living with HIV/AIDS.
- **Training** for volunteers, home based care assistants and nurses.
- An orphan sponsorship scheme.
- Financial support for particularly needy families.
- Research and evaluation of project activities.
- **Participation** on a variety of significant national and local bodies.

Over the next 5 years, the College of Medicine Home Based Care Project seeks to:

- Consolidate the service it has developed in Bangwe and Limbe, extending provision of care to increasing numbers of patients. The team will aim to support 2000 new patients, 8000 old, and make 15000 home visits.
- Assist the District Health Management team to expand home based care to the areas of Blantyre which currently have no service.
- Become a national resource for the Ministry of Health, NGOs and other home based palliative care providers, offering advice, advocacy, training and support.

Looking back on 2012 and 2013

Since the last report to private donors in December 2011, we can report that the project continues to function well, staff are motivated and enthusiastic, they have maintained the increased catchment area, liaison and referrals from the health centres are good and the continued need for home based and palliative care is as pressing as ever.

Nursing care

The following table shows how the team continue to reach high numbers of patients despite reduced staff numbers.

Community Home Based Care (CHBC) service	2008	2009	2010	2011	2012	2013#
Number of new patients enrolled on project in the year	591	246	515	524	418	159
Total number of persons who received CHBC services in the year	5168	1787	2192	5243	4973	2922
Number of community home based care visits by health care worker/s in the year	6352	2426	3600	5861	5798	3190
Number of community home based care visits by volunteer/s in the year	12984	4790	6940	12097	11629	6552

- Jan-Sept months only

A key nursing challenge is that many patients present too late for effective treatment or referral. Another major problem is lack of food. Without food, chronically sick patients are reluctant to take the required drugs and the effectiveness of anti-retrovirals and drugs such as antibiotics and TB therapy is reduced. We continue to be grateful to the Chard District nurses and Lloyds Pharmacy in Chard for ongoing supply of unwanted dressings. The regulations for the supply of morphine have been tightened and the project is no longer allowed to keep large amounts. However there is a good relationship with the palliative care doctor at the government hospital to ensure morphine can be accessed readily for named patients in need. All staff are involved with regular training and refresher courses are given for the home based care volunteers. Mobile phones enable volunteers and nurses to communicate when in the field. We would be grateful for any unwanted ones you are able to donate to the project. The same applies to working laptops. Norton Gondwe, the project manager, graduated from his MPH in 2012. He indicates he wishes to continue as manager of the project and is seeking a scholarship through the College of Medicine to pursue a PhD.

He has sent stories of four patients for this report:-



Rose – 32 year old with 3 children, all HIV positive. Recurrent episodes of TB and now the possibility of multi drug resistance.



Bita – Born in 1934. Cervical cancer since 2009 receiving home based care for 4 years. Oral morphine being administered by nurse Lydia, specialist in palliative care



Pius – Born in 1975, HIV positive, wife and daughters ran away due to husband's illness. Home situation very pathetic with no food and poor shelter.



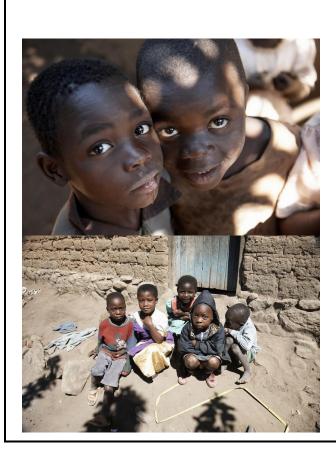
Alice – born in 1980. Deaf and dumb and HIV positive . Also has a AIDS related cancer since 2012. Communication with nurses is by sign language. She is a challenging case for the team.

Support group

The 'positive living' support groups are still operating but no longer require any funding from the Trust as they incur no costs. Currently, there are 2 groups each with about 80 members, which meet weekly. Fortnightly clinics are run by the project staff covering nutrition, health, adult literacy and income generating schemes. The three treadle sewing machines purchased for the group in 2007 are still being used to make and sell things and at least 30 people have trained as tailors.

<u>Orphans</u>

In 2010 we were supporting 17 orphans with sponsors donating approximately £5,500 annually to cover their school and college fees, uniform, food support, transport and stationary. The majority of these orphans have successfully completed both secondary and vocational training and are now in meaningful employment, able to support themselves and members of their family. We are now supporting just 6 individuals -2 special needs children who are still at school, 1 girl who is in her last year of secondary school and 3 students who are in further education or vocational training. This past year we have seen 2 orphans complete their vocational training and become fully independent. One girl has gained a diploma in tourism which the highest qualification being offered in the country and another girl has full time employment also in the tourist industry. This next year we should see Harold graduate from the College of Medicine as a laboratory technician, Thokozani gain a certificate in journalism and Phyllis obtain a diploma in agriculture. We are grateful to all our sponsors who have helped so many vulnerable and needy children over the years.



There are so many orphans in Bangwe. But Malawians are admirably resilient, resourceful and cheerful. They have an amazing capacity to cope under extremes of poverty and need. The extended family absorbs orphans without demur and many households, if asked, do not know how many are living under their roof. Stories abound of maltreatment of orphans and it is true that they are usually at the bottom of the pecking order, but few young children are totally destitute. Many never have the chance to complete primary, let alone secondary school. Very young children are expected to care for sick parents and relatives, fetch water, find food and wash the clothes.



Patient financial support

A small amount of funds are made available to patients in extreme need to help them pay for essentials such as food, transport to hospital, repatriation to home village if destitute and sick with no one to care for them, and loans to start a small income generating business.

Research and evaluation

The local director, Dr Adamson Muula, has sought research funds to carry out some research over the last 2 years, so far unsuccessfully.

Finances

From the project's inception, salaries, drugs, some training and some vehicle maintenance have been funded by the Diana, Princess of Wales Memorial Fund. Orphans, transport, a drama group, patient support, the support group and some salaries have been funded by private donors and smaller grants; money channelled via the Malawi Home Based Care Charitable Trust. The Diana funding has now come to an end but the project is financially secure until July 2014 with the following funds:

- approximately \pounds 3,000 underspend in 2013 due to massive devaluation
- £28,000 from the Malawi Home Based Care Charitable Trust which includes £5,000 from the Network for Social Change Fast Track Fund (a grant made in March 2013 but which has not yet been required due to the devaluation).
- Funds from private donors estimated at \pounds 4,000.

Project costs for a full twelve months, including a 25% pay rise, are approximately £54,000. We currently have funding applications pending with Comic Relief and Elton John Aids Foundation, which, if successful, should come on stream mid-2014 and fund activity for a further 5 years. If unsuccessful, 2 very generous supporters have offered to cover any shortfall in project costs to the end of 2014, enabling staff contracts to be renewed for a full year, Jan – Dec 2014. Any support you can give us to minimise this potential shortfall would be most gratefully received. In addition to a straight forward donation (see <u>www.malawihbc.org</u> for details on how to donate), you may like to support us by:



One of our volunteers

information please don't hesitate to get in touch.

• Having a stall and/or running a raffle at a local event, e.g. at a Christmas fair or pantomime. We can provide you with literature, photos for a display and bead badges made by the support group with the AIDS logo and the colours of the Malawi flag.

• Doing a sponsored event such as a sponsored run or cycle. Anna, Dan and Emily have all done this for us in the past raising over $\pounds 6,900$ in total so well worth the effort. We can provide advice and background information for sponsorship forms.

• Buying our Christmas vouchers for friends and family – see <u>www.malawihbc.org</u> for details.

Thank you again for your support of the Malawi Home Based Care Charitable Trust. For any further

Kate Handley and Cam and Claire Bowie, <u>kate@malawihbc.org</u>, <u>www.malawihbc.org</u> 01460 221903 / 01297 34985