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Dedicated to giving practical and emotional support to all in the Debenham area who care for those with Dementia.

A Vision for Caring

(Integrating Health and Social Care in a Rural Environment)

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Abstract

This paper proposes a new direction to the care of the elderly frail in a rural environment. It argues that by adopting a person-centred, community-led approach that, not only, can the quality of care be significantly improved, but that the cost-benefits associated with this care will be substantial. A conceptual model and a possible implementation are described in which health and social care, domiciliary, day, very sheltered, nursing, secure, respite, and other forms of care are integrated within a community-led, community managed framework.

The significance of this work is that it has arisen spontaneously from concern in a rural community. It is considered that a model in which the community takes the lead in supporting the elderly frail and, where and when required, draws in the professional services of the local authorities, the NHS, the charities, and the independent care providers is one which naturally leads to an optimum utilisation of resources and a maximisation of the quality provided.

Preface

The authors appreciate the there are three ways in which they can consider and describe the potential for change that The Vision for Caring represents.

The first is to take the "professional" viewpoint which is best categorised as the "service provider" model. In this we would argue that by taking "The Debenham Approach" an exemplar of best possible practice would be provided – one in which social care, health care and housing support come together (integrate) to supply the necessary services and, not only meet needs, but do so at a significantly reduced cost to the public purse.

The second is that "social enterprise" can be enabled to adjust the balance of responsibility and service provision between the government and the community. In so doing, the quality of health and social care delivered to those in need will be higher and more individually directed – "the community <u>does</u> know best what is needed (but it may not know quite how to deliver it) – but also at a lower price.

The third is to explore the viewpoints of those who need support i.e. those who care for an elderly frail person with dementia or any other illness that makes them dependent on others, and, of course, those they care for. Then, given an understanding of their needs and frailty, to propose how we as our community working with our local authorities, our NHS, our charitable agencies, etc can best provide a level of care which we would be proud to hold up as "best practice" – an exemplar of what can be achieved if we want to.

In this paper the authors have adopted the third perspective, but would hope that the reader would be prepared to positively interpret the content according to their own viewpoint. No matter which viewpoint, we would argue that "The Vision of Caring" offers a new and exciting prospect for health and social care in the rural and semi-rural environment – one in which a quantum step forward in care can be achieved but at lower than current level of expenditure – truly a win / win situation.

The authors appreciate that a large element of achieving the aims requires investment in "bricks and mortar" but would ask the reader not to view it in those terms – it is about providing the organisation and facilities to enable an innovative and next generation structure for "Caring in the Community".

Introduction

You live in or around Debenham. Imagine a time when your Mum, Dad, Husband, Wife, Partner, etc doesn't have to move 7, 10 or 14 miles to be cared for in the way you feel that they deserve. A time when you can enjoy your relationship without the exhaustion of being "on call" 24 hrs a day, the worry of what might happen when you aren't there, the fear of what you would do in an emergency, and having to be continually driving back and forth (assuming that you do not have to depend on public transport). Yes, you want them to stay in their own home amongst their familiar surroundings and in touch with their friends, but if that can't be, you would like them to be nearby where you and those they know can pop in and help them as they once helped you. Somewhere familiar, somewhere "just down the road" so that they can, with help, still shop at the same shops and have coffee at the same café. Is this just a dream, a vision that can never be? It doesn't have to be - we can make it a reality. It will be a great challenge but it can be done.

Why should anyone have to leave their community just because they have become increasingly frail? Why should they end up in a district hospital just because there are insufficient facilities for them to be cared for in their community? Why should they have to move away in order to receive the support of sheltered, residential or nursing care? It does not have to be - we can make it unnecessary. It will be a great challenge but it can be done.

A Community-Led Approach

There is an alternative to the way services are currently provided, and that is for our community to take the lead and ensure that the best care is provided right here within Debenham and the surrounding villages, and that means:

Community services to encourage active and social well-being

Social care and support in the home

Day care facilities throughout the week

Guided access to quality information and advice

Respite Care for carers to have a break or in emergencies

NHS consultation and outreach services

Very Sheltered Housing with integral social care support

Secure Care for those who may be a risk to themselves

Nursing Care for the very frail and for those at home

Residential Care for those who need a more intensive level of support

The objective is to meet the needs of each one of us as we progress through our older years, and to do this naturally, and with the minimum of stress and disruption. A tall order indeed, but we have a vision to match your imaginings. A scheme which would integrate health, social, domiciliary, day, very sheltered, residential, secure and nursing care[1] - that could be the model for:

Caring in the Community

Caring by the Community

Caring for the Community

This should be an aspiration for all rural communities (and maybe some others as well!).

There is no reason why such a dream should not be affordable. In all probability such an investment will save money across the board - within the NHS, local authority adult care services, charities and voluntary organisations, the government social security benefits budget, etc. It's a matter of treating the problem "in the whole" and breaking down the organisational barriers. Integration and sharing of resources together with the mobilisation of the voluntary sector can easily outweigh the notional benefits of "scale and specialisation".

It would be all too easy to create a "community for the elderly", a "silver paradise", or a "grey ghetto" depending on your viewpoint. These are an anathema to The Debenham Project. This project, although deriving its initial focus from concern about the carers of those with dementia and those that they care for, is committed in the longer term to supporting all who, as time goes by, may not be able to independently look after themselves, and may need care and support from family, friends, the NHS, the local authority, etc. - and to achieve this within their own community. It seems intuitively obvious that just because someone becomes frail, they do not cease to be a valued member of their community. A "complete" community should include and involve all ages in all their diversity and capabilities. A community can be judged by the way that it cares for all its members.

Thus the vision requires whatever facilities are provided to meet three key criteria:

Do they seek to enhance the quality of life for the carer and the cared-for?

Do they seek to encourage and enable the cared-for to live a full life within their community?

Do they seek to support family and friends in all aspects of their caring role?

The Debenham Project Approach

The Debenham Project comprises two threads:-

The local provision of practical and emotional support. This is manifest as a range of services:

- Information and advice
- Activities and social sessions
- Lunch clubs
- Respite provision
- Carers Club and Info Café
- Access to paid social care support and home help
- Confidential telephone support
- Medicine management
- Locally provided consultant-led specialist clinical services

These are things that are focused on dementia (but not exclusively so) in the recognition that this is the immediate and pressing problem. They benefit the carer of someone with the symptoms of dementia and the person they care for, and have already being put into operation - This is the **"Here and Now"** thread - and its nature is fully described on our website (www.the-debenham-project.org.uk) and in other publications.

The other thread is concerned with a long term vision in which health and social care are drawn together, and domicilliary, social, day, very sheltered, and high dependency/intensive support (residential, nursing and secure) care are integrated - The **"Vision of Caring"** thread[1]. It is this thread that this paper is directed towards.

The Nature of the Problem in a Rural Area

Debenham together with its surrounding villages is fairly typical of the further end of the scale running from city through urban, suburban, county town, market town and finishing with the rural environment. It has a population of approximately 2,500 and a further 2,000 live within 3 miles, with another 2000 in the band between 3 and 4 miles distant. So we think of a potential catchment population of 6,500.

At the centre, Debenham is a large rural village in Suffolk with a balanced mixture of medieval and modern houses and buildings. It is a natural centre of population, with a number of shops, a small supermarket, a post office, a pharmacy, a GP practice, a couple of pubs, a primary school, a high school and a community centre. The nearest larger towns are more than 7 miles distant and the County town of Ipswich is 14 miles away. It is to these towns that those, within our "4 mile" catchment area, must look to for the provision of services other than GP and community nursing health care. It is typical of many communities across East Anglia and the UK in general. It is important to distinguish such communities from the semi-rural towns and urban communities which are, so to speak, located further towards the more metropolitan centres of population. There are demographic and geographic differences that make the fair provision of health and social care services at the rural end more difficult but, on the other hand, there are sociological features which are positively beneficial e.g. a strong community spirit, a "good knowledge of, and friendship with, our neighbours", and a general willingness to give time to the support of "good causes" (especially when linked to "having a good time!").

Within this catchment area we can estimate that there are already over 70, and by 2015 there will be well over 100, people with recognisable symptoms of dementia[2] and that each one of these will involve someone in a caring role together with a level of support from County Council Adult Care and Community Services, the NHS, charitable agencies, local voluntary support, and informal help from family, friends and neighbours. The nature and level of support will vary tremendously, from a relatively minor amount of 5 - 6 hours per week to full time nursing/secure and social care in private or supported accommodation. Currently, it is estimated that the average overall cost, to the community, of social, health, nursing, secure, etc care per person with dementia is just over £25K pa[3]. This figure is almost certainly a significant underestimate, especially of the costs related to the family carers, and of the opportunity costs associated with NHS admissions[4] and of emergency interventions due to a lack of appropriate care facilities being available in the local community[5]. Further costs arise in rural and semi-rural environments where access to, and management of, those services that are available is subject to significant travelling distances[6]. Additionally, the changing age profile suggests that, as the number of very elderly people increases, the average cost per person with dementia will also increase markedly. If a benchmark of £30K per person pa is taken then we can estimate the overall cost of dementia in and around Debenham will be in the region of £2.1M - £3.0M pa.

When it comes to the longer term view of "Caring in the Community" those who have symptoms of dementia are just one, albeit a major, element of the equation. There are many other older members of the community who would benefit from support because of their increasing frailty, and who could enjoy a much improved quality of life, and a substantially reduced risk of personal injury and hospitalisation.

An historical analysis of the numbers of older people, living in the council wards, in and connected to, the catchment area[7], with care needs has been used to estimate the number of persons with a need for different types of social care support, accommodation, funding, etc. for Debenham and the surrounding villages.

Domiciliary/Flexi social care support	110	
Very Sheltered accommodation with integral care support	40	
Higher/Extra care (often annexed to the above)	21	
Residential/Nursing care accommodation	30	
Total		201

Of these our current research indicates that 42.5% of the total will have significant symptoms of dementia[2,7], leading to the following broad spectrum picture.

Older people with care support needs:	Dementia	85
	Other	116
	Total	201

These figures are based on the latest estimates and statistics (years in the range 2007 to 2009) and have not been adjusted for demographic changes since then. All evidence suggested that they are underestimates but the exact degree is unknown. Projections into the future suggest that the scale of the problem will have increased by more than 20% by the year 2020.

Taking this into account and using the above benchmark of £30K, we may approximate the overall future (normalised to 2010 figures) financial cost of caring for the elderly frail population in Debenham and its surrounding villages to be somewhere between £5.9M and £8.5M pa. These costs are based upon the current

way that care is provided by the NHS, the Local Authorities, charities, and informal family carers. They do not take into account changes in the pattern and cost structure that might be introduced in the near and medium term.

Nationally, the expenditure on social care for the over 65s in 2008-09 was approximately £9B[13], which very roughly translates to £975,000 in the project's catchment area. The annual cost to Suffolk County Council of **means-tested** social care in the Debenham area is in the region of £1.05M[7]. This indicates that the cost of care in our rural environment is noticeably greater than the national average. However, we must recognise that public expenditure on social care is, unlike health care, means tested and there is a major element of self-funding. The additional element of cost which is borne by the clients is 62% in the case of residential and nursing support and 32% for domiciliary and day care[13], leading to an approximate annual cost of about £1.5M.

To assess the overall expenditure on all **paid** social care (local authority and privately funded) we need to add the costs incurred by those people who do not qualify for local authority support on financial grounds, but whose needs are nonetheless as great – they are largely invisible to any quantitative analysis. Although we cannot directly obtain this cost we may be able to fairly accurately estimate the 'cost per client' from the above figure since the needs of those who qualify are unlikely to be any different from those who do. [It is perhaps true that the cost per person of social care provided by the local authority is less than that purchased directly by more "affluent" clients but this difference may be discounted in the initial circumstance]. The difficulty lies in establishing the numbers of these self-funders. By using local knowledge of individual family carers and those they care for it is thought that the proportion is unlikely to be less than 30% and may be significantly more than 50%.

Similar calculations must be made with regard to supported housing such as the various types of residential and sheltered accommodation. The overall expenditure on housing development and benefits for the elderly frail in the catchment area is not known but is likely to be significant and of the same order as that for social care. It is debatable whether this should be included in the overall "care bill" but it is a cost to the taxpayer that must be considered in developing any integrated approach to health and social care which is based upon any form of very sheltered/residential/nursing accommodation.

These two elements (social care and housing development/benefit) represent the major components of the costs to the local authorities of providing the services at the moment. There are smaller but also important expenditures on social welfare for example Customer First, telephone support, advice and information, home help, etc.

Although the unpaid contribution of family carers and volunteers is generally recognised as very significant, it remains difficult to account for it other than by determining the lost benefit to the community due to their full-time commitment to the person they care for. We might consider this as a "socio-economic" opportunity cost. At its minimum, it is estimated to be about an average of £7,200 pa for each family carer[17]. It must be recognised that, as the need for care progressively increases, the family carer should be increasingly costed as providing full time 24/7 cover. This roughly sets a minimum value of about £1.4M pa.

Social welfare is one "half" of the needs of the frail elderly. The other "half" is health care. The current annual budget for NHS Suffolk (the primary care trust) is £850M supporting a population of about 600,000[14,15]. Based on this and that something in excess of 40% of NHS activity is directed towards the over 65 age group, we roughly

estimate the NHS expenditure on health care for the over 65s in the Debenham area to be of the order of £3.7M pa.

Using the national statistics relating to hospital episodes it is roughly possible to estimate the demand currently placed upon the district general hospital by the elderly population of the Debenham catchment area. The estimated number of hospital episodes involving persons over 65 in 09/10 was 568 with an average stay of 4.87[4,8,9] days. The average cost of each episode was £2,600 leading to a total cost of about £1.5M. A & E attendances for the over 65 age group numbered 287 at a cost of £27K but 57% of these attendances led to in-house assessments with a total additional cost of £0.25M.

An important cost element lies in the provision of local health facilities is the annual investment in GP and community nursing for which total expenditure amounts to approximately £1.0M pa[,16].

In total, the currently obvious and measurable cost of health and social care in Debenham and the surrounding can be broadly estimated to be £6.6M pa. However, this figure does not include any element of housing support. Furthermore it does not take account of the "financial cost of distance" that particularly applies in a rural environment. In addition, if the "private" expenditure on care for the frail elderly and some of the indirect costs are included, it is probable that the true cost will be significantly nearer to £10M pa.

It is recognised that this figure represents the "scale of the problem" and needs to be more accurately calculated. However, it defines the potential for cost savings by developing an integrated community-based health and social care approach.

Integrating Caring in the Community

We argue that by adopting a local integrated approach to health and social care, significant reductions in the above expenditures can be made and, more importantly, real improvements in the "quality of life" for people and their "illness prevention" can be achieved. Analysis[10,11,12] suggests that reductions in hospitalisations, and emergency interventions, etc of 30% or more may be realistic in the long term. The length of hospital stays could be cut dramatically by the provision of quality general nursing and post-hospital medical care in the patient's community. Furthermore, the social cost benefits derived from prevention of illness, reduction of patient trauma, and general improvement in quality of life, although difficult to quantify may be equally important.

The key question is: "How can we achieve such financial savings and also achieve significant 'quality of life' improvements for the "customer base?" (i.e. those who would benefit from support).

We believe that by approaching the problem from a "whole person" or "whole family" perspective, it is possible to locally address the needs of both the carer and the cared-for in a more straightforward and simple fashion. Most of the needs of the elderly could be met in their own community but, because this is not currently the case, major emergency and critical interventions by the NHS and Adult Care services are frequently required. Responding in these circumstances is very expensive and often has serious longer-term implications (e.g. extension to waiting lists, inaccurate diagnoses, inappropriate admissions, bed-blocking, irrecoverable deterioration in patient well-being, family distress and dissatisfaction, social worker overload, inadequate delivery of social care, inappropriate decisions, etc).

It can be argued that a community-based approach to health and social care, which brings together the local primary health services (the GPs and Community Health), Adult Care, public services and the local community, will substantially reduce hospital admissions for the elderly and assist them in returning to their own homes (or community) after any such episode[9]. In so doing, specialist care may be more efficiently deployed for the benefit of the population at large.

A Conceptual Model for the Rural Environment

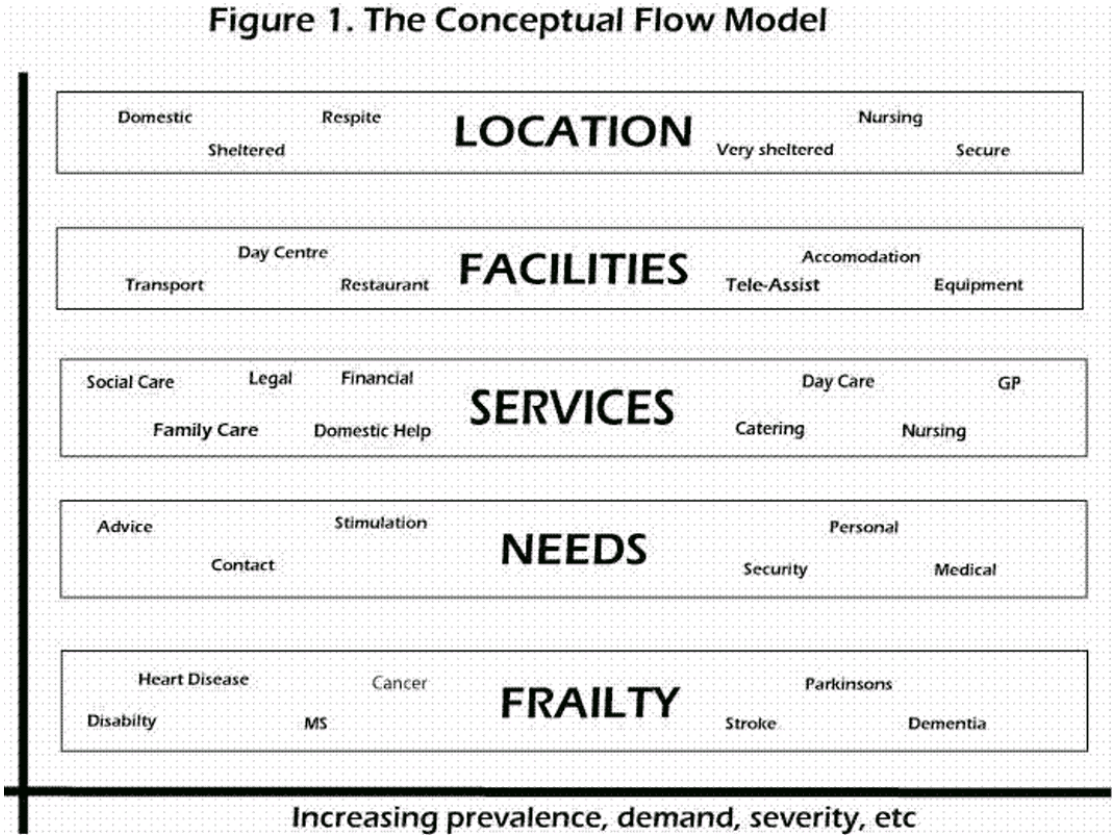
In seeking a "natural" solution to the problem of providing appropriate and desirable care for frail elderly members of our community, it is essential to examine the pattern of their support needs as they progress through their later years.

Current attitudes and models seem to be based upon the following assumptions.

1. That progression from active to dependent is a monotonic and irreversible fact of getting older.
2. That as people get older their contribution to their local community becomes less important.
3. That, given a choice, most elderly people would seek to stay in their own homes.
4. That residential**, nursing, or hospital care are the only options when caring in the home is no longer realistic.
5. That when there is a medical or social crisis it is essential that the elderly person is admitted to a remote district general or mental hospital.

The authors argue that each of these assumptions should be questioned. It may be the case that, as we age, we do become more frail and dependent on the help of others, but it does not imply that just because we suffer a crisis that it means that we are unable to resume the quality of life that we enjoyed beforehand. To consign the older generation to a marginalised "old people's home" existence is to deny their wisdom and experience as a valuable element of the education and enjoyment of the younger generations – and particularly, the grandparent/grandchild relationship. To give up one's family home is a major decision, but many elderly people recognise the difficulties that their homes present and would happily move to more appropriate accommodation if they could remain within their own familiar community. When there is a crisis that makes caring in the current home impossible, the option of being "put in a home" is an understandably negative concept. Many medical and social crises do not require the full facilities of a district hospital and can be more successfully managed locally if adequate local nursing capabilities exist. These are concepts which are central to the objectives of the HAPPI (Housing our Ageing Population: Panel for Innovation) report[21].

We believe that by mapping the provision of services and facilities onto the pattern of individual social and health needs that a "natural" and integrated care support structure can be envisaged. This is the basis of our proposal for a "Vision of Caring".



Note: the order of the individual titles within the boxes should not be thought of as significant although each is likely to be of increasing prevalence/importance with age.

This is expressed in figure 1. Broadly, there is a flow, from left to right, of increasing frailty as we age. The age-scale for an individual varies enormously and it is by no means continuous – crises such as a fall, a major medical or psychological episode, or the onset of a serious illness usually lead to a step change. Alongside this flow there is a flow of needs which can be expressed in terms of the individual's physical and mental difficulties in independently managing their daily life, and in maintaining their quality of life. We can map these needs onto a flow of services i.e. what is needed to satisfy the individual's needs through the support provided by family and paid carers, together with the professional services of the local authorities, the NHS and the charities. Finally, we may map the provision of physical facilities onto this model in terms of the availability of aids in the home, day care and other community capabilities, very sheltered accommodation, and high dependency accommodation such as nursing, secure, and respite care beds.

Without any doubt the purpose of social and health care for the elderly is to reduce the effect of ageing on the individual and on those who care for them – to maximise their potential quality of life and to minimise the impact of medical or psychological episodes – and to enable them to continue to be contributing members of their community.

The authors argue that it is possible to provide health and social care services locally in a rural environment such that they are responsive to the needs of the individual as and when they are required and that this can be achieved efficiently and to the best quality standards. In fact we believe that not only can a quantum step forward be

achieved in standards of care, but also that the overall cost to the broader community will more than offset any increased cost at the local level.

The following concept model called the "Vision of Caring"[1] has been developed as a means of testing this belief.

Implementing A Vision of Caring

This concept model is expressed as a design for an embedded integrated health and social welfare scheme which includes the services to be provided, the organisational structures, the financial requirements and costings, the planning implications, the socio-economic elements, the community involvement, the client base, and many other aspects.

It is stressed that this is just one possible design (the "Vision of Caring") developed for one rural community (Debenham) and that should it prove viable and a decision taken to turn it into reality, many other imaginative designs would have to be explored. The reader is cautioned against focusing too much on the potential physical (bricks and mortar) realisation. The purpose of the model is to show that the ideas that have been presented are practically, organisationally and financially achievable. It would be of direct application across a wide spectrum of rural communities across the UK and readily adaptable to more urban environments.

Figure 2. (below) shows the basic concept.

The proposed care scheme will provide the accommodation, facilities, services, finance, and organisation that are needed to fully integrate health and social care, domiciliary, day, very sheltered, secure, and high dependency (nursing, respite and special residential) care in the Debenham* community environment. It will seek to provide services and support such that the local community will:

a) naturally accept it in the same way as the NHS has, in the past, been generally accepted as "being there when we need it",
b) develop an appreciation that it is not necessary to leave the community when we become more elderly and frail, and
c) no longer need to travel significant distances to access the quality support services that it requires.

It must especially recognise the needs of family** carers and their continuing role in the care of their loved ones and friends.

The essence of the scheme is based upon the desire to enable the person needing support to remain in their own home as long as possible. However, when that may prove no longer desirable or possible, best practice supported housing accommodation should be available which is still within the community. Familiarity with their community and personal relationships are retained - and their care support continues to be provided by the same individuals. In other words, it should not be a question of a total upheaval, but more of a moving to a more appropriate living space where their safety, security, quality of life, and care can all be enhanced.

Inevitably, some will need care of a temporary (eg respite care) or a more specialist/intensive nature (e.g. nursing, secure or special*** care) and the scheme should provide this, albeit at a limited volume - it should not be necessary for someone whose frailty has become very significant to be moved to a remote specialist home.

This scheme is centred on a very sheltered housing unit with "satellite" units for high

dependency/intensive support (secure, nursing, respite and special care) beds. In addition, it contains a community services unit catering for the provision of social and health care in the community in general, for day care services, for GP and community nursing, and for other community directed activities.

In this way resources can be shared naturally and staffing costs minimised, but the important feature is that there should be no boundaries or barriers between one form of care (or provider) and another.

In the design of the scheme we are seeking to implement the natural pattern of "flow" or "progression" through the scheme as indicated in Figure 1. This shows the various stages or levels of care support beginning with informal family care in the home which is reinforced by help and services provided by the local community. Those with more significant forms of disability may need a range of day care and domiciliary services coupled with GP, nursing and specialist health care. For some, the option of very sheltered accommodation with integrated social care support will be appropriate when coping in their current home has become difficult. Social and health care support in this environment is much easier and more cost effective to provide to a high quality standard. It can provide an increasing level of care up to that provided by traditional residential homes but still retaining the independence of living "in their own home". However, as the average mortality age increases more of the elderly will fall into the categories of "very frail" and "at high risk" when any accident or medical incident may prove life threatening, or at least lead to significant irreversible reduction in mobility, mental capacity and quality of life. Today their needs usually require hospitalisation but in practice the provision of general nursing care coupled with an "intensive" social care support regime can meet the needs of the majority without them being subjected to the trauma of hospitalisation.

In the design of the scheme "the creation and implementation of best practice" takes precedence so that an overarching objective is to enable all who benefit from its services to achieve and maintain active involvement and stimulus within the community. The classic perceptions of "residential care homes", "home help", and "social care" as services for the safe and secure management of the elderly has no place - this scheme is centred on supporting individual frail elderly people and their carers in seeking to maximise their quality of life. Thus it is essential that the scheme encourages and facilitates the involvement of carers, cared-for, tenants, residents, volunteers, etc in the day to day running and activities of the scheme. This will be doubly important in the care of those with symptoms of dementia.

At all levels the model has four major organizational elements (figure 2):

1. Domiciliary support.
2. Day care and community support
3. Very sheltered accommodation with integrated social care support
4. Extra care residential and nursing support

Figure 2. The Conceptual Design

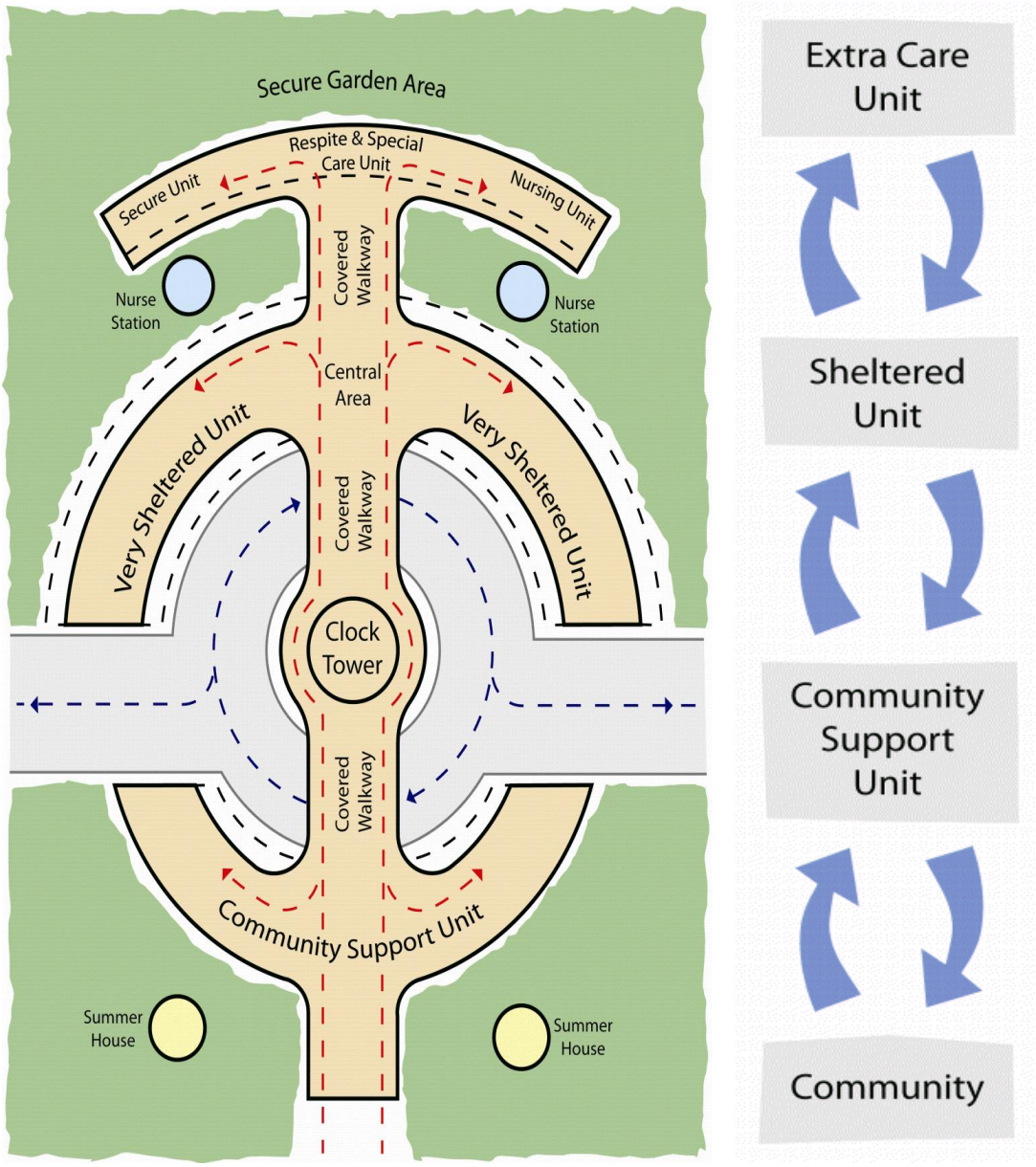


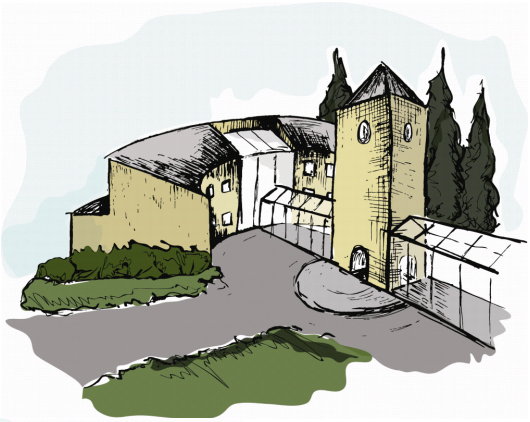
Figure 2, shows the physical level in terms of the accommodation that supports the model. The community at large surrounds the scheme encouraging the principle of embeddedness. It is considered vital that such a scheme must not be consigned to the boundaries of the community – in some way separate or an extension – such that those that it supports remain able to take a full part in the life of the village/town despite their frailty. It must be within an easy walking distance from the shops, cafes and, village/town centre.

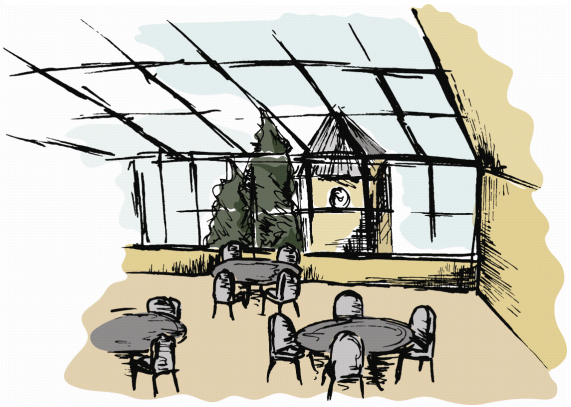
At the physical level the model comprises four components:

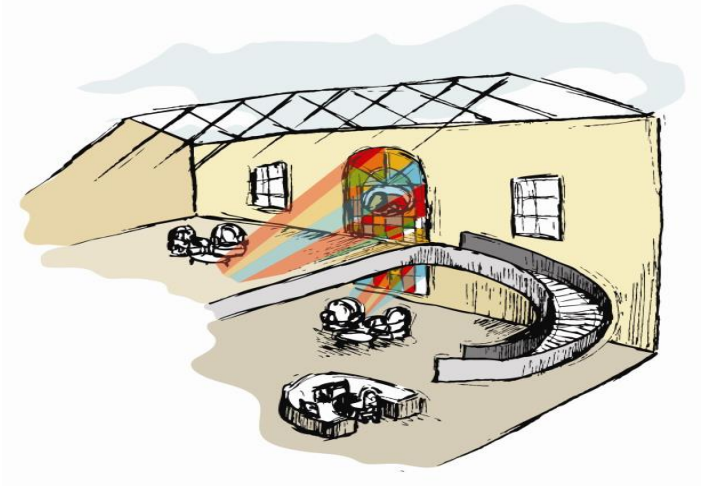
1. The community support unit
   This unit reaches out into the community and supports services such as paid social care, domestic help, community nursing, day care, voluntary work, outreach work, satellite GP surgery, specialist dementia and geriatric clinics, and social work. At the same time it also looks inwards to support those in the very sheltered and extra care facilities.

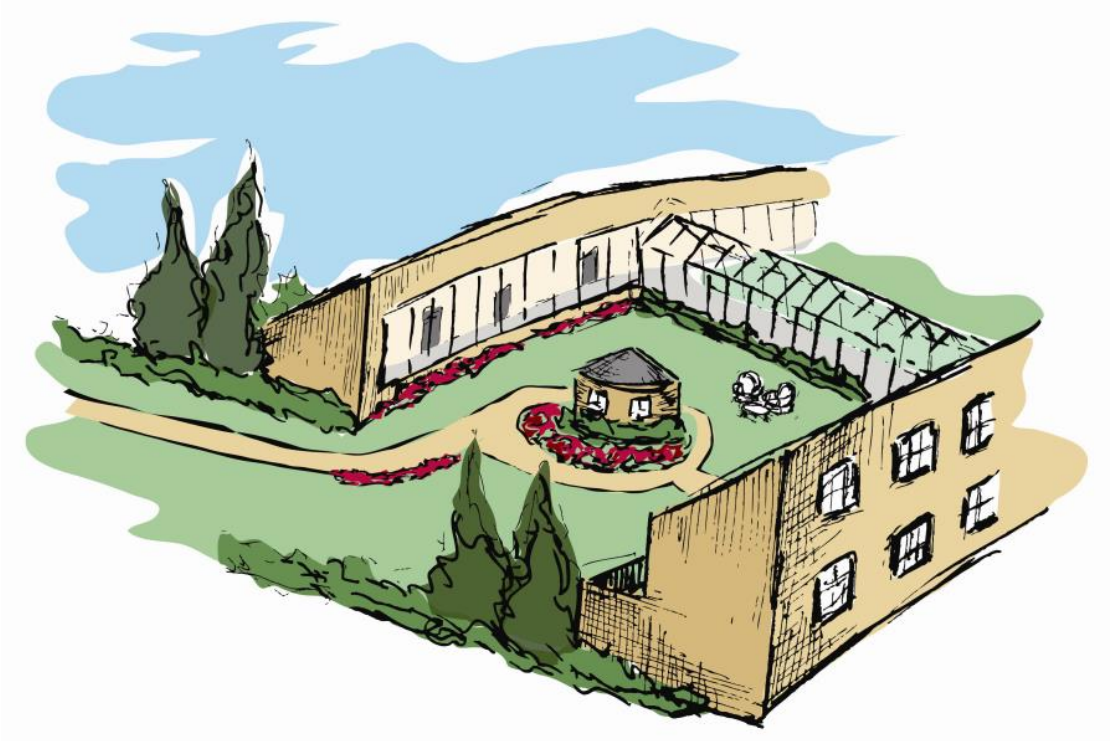
2. The very sheltered unit
   Approximately forty 2/3 bedroom flatlets with integral care support packages and the prefitted capability for the general nursing of many medical conditions of old age. The unit has the facility to provide extra care to a level equivalent to that available in residential care homes.
3. The extra care unit
   Approximately 18 beds designed to flexibly provide full general nursing, secure, respite, assessment, and high dependency residential care. The mix is intended to be fully adjustable to the dynamic need.
4. The shared community social and leisure facilities
   This unit provides community capabilities to encourage social interaction between the residents, the staff of the scheme, and the community at large. Typical facilities might be supporting exhibitions, school liaison, meetings, lunches, training, talks, etc. It is also expected that the unit will house a library resource centre as well as other community facilities.

It can readily be seen that the design is intended to map the flow of frailty, needs, and services described in the previous section. The scheme has been modelled in terms of its specification, possible design, financial viability, etc to demonstrate that it is a fully practical prospect.









Artwork by Michael Carruthers

A number of important features are inherent in the model:

1. The people who provide social care, domestic support, nursing, etc are the same irrespective of whether they are supporting clients in their own homes, in the very sheltered units, or in the high dependency area. This ensures continuity and familiarity of care, and encourages long term positive relationships between professional carers and their clients.
2. The progression through the scheme is not monotonic. The model seeks to provide higher levels care as and when needed, and to facilitate return to home or sheltered accommodation as rapidly as possible. Too often a medical or social trauma results in a permanent increase in physical or mental frailty.
3. The extra care unit should not be thought of in terms of a cottage hospital, a nursing home, or a residential home. It should be considered more as a satellite facility that has the ability to be used in these capacities as is appropriate to the individual's needs. It is intended to be fully flexible and provide for both temporary nursing and respite support, and also for longer term secure and intensive residential care.
4. The involvement of the population as a whole is encouraged by the availability of community facilities for arts and social occasions, exhibitions, library, educational functions, etc. The embedded nature of the scheme within the local community positively enables family carers and volunteers to informally continue their caring role

The likely cost of developing such a scheme as a Not for Profit Social Enterprise will be a little over £10M and the operating costs, including capital servicing, are expected to be about £2M pa[20]. Given that a small measure of the savings that will accrue to the NHS and Adult Care are transferred to the scheme a break even (at least) position can be confidently assumed. The authors have calculated that based upon the potential demand outlined above, and the expected pricing strategies for supported and private services, the scheme is financially viable, and as the full potential cost savings become realized there will be opportunities to further enhance the quality of care which will be available.

Financial and Social Benefits

The fundamental feature of the proposal is that it can satisfy most of the health and social care needs of the over 65s within the community - treatment in, and admission to, a district general or acute hospital being primarily for specialist or critical care. It means that nobody needs to leave their familiar environment to access services or receive the care appropriate for their condition or degree of frailty. In so doing, it meets the aspirations of the over 65s that seek to be cared for by, treated by, and remain within their local community. It is believed that if this scheme can be implemented it will bring a wide range of benefits both in efficiency and cost savings, but more importantly in, less quantifiable, improvements in individual (carer and cared-for) quality of life. The "top twenty" benefits from the community standpoint might be as follows (in no particular order).

1. A high level of voluntary support
2. Familiarity with the carers and cared-for.
3. Straightforward and local access to services (assisted if required)
4. A local and informal "first port of call" for carers
5. A flexible and tailored approach the delivery of services to the end-users
6. The ability to monitor and manage the quality of service provision
7. Activities and services focused on local and individual needs
8. An 'ownership' of the problem and willingness to initiate further new services
9. Encouragement for carers to seek help and to support each other
10. Increased wellbeing of family carers
11. Stronger relationships within the family and the community
12. Continuing social and intellectual involvement
13. Reduced demands on the GP practice
14. A more effective delivery of social care support
15. Reduced hospital incidents and emergency admissions
16. Lower hospital bed days and reduced bed-blocking
17. An increased provision of intermediate and high dependency care beds
18. Resource sharing
19. The immediate availability of resources in emergency situations
20. Improvement in general level of health and welfare of the over 65s

Considered at the strategic level, it is believed that if this approach is adopted it will reduce NHS and Adult Care costs and improve average health and social wellbeing by preventing illness (in the case of dementia, by delaying its onset, slowing its progression, and avoiding emergencies if at all possible) and improving care (by enabling more to be given within the home and by the local community, and reducing falls, accidents, medicine mistakes, etc which are common for those with dementia) and achieving earlier diagnoses of dementia and other serious and progressive illnesses[11,12].

The approach that is advocated will enable financial savings to be made in many aspects of the care of the elderly frail. However, it is difficult to quantify many of these in the absence of adequate financial data at the local level. Nevertheless, some estimates may be made in respect of A & E attendances and hospital episodes. Currently the expenditure amounts to close to £1.8M pa[9]. It is known that by introducing an integrated and team approach at the local level a major reduction in these admissions can be achieved. We believe a figure of 30% to be realistic leading to potential savings of £0.6M pa. In addition, the provision of facilities to "unblock" hospital beds would yield a likely benefit of about £140,000 pa.

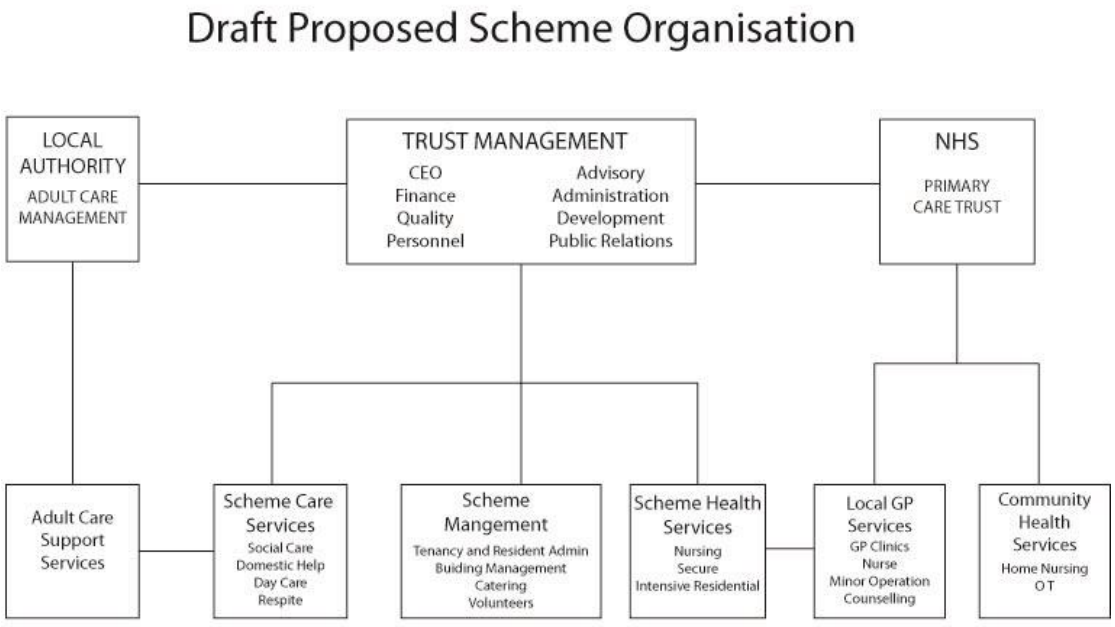
It is also possible that social care costs can be reduced significantly. The project's philosophy is to try to help people to remain in their own homes as long as possible –

very sheltered accommodation being made available when this is no longer viable. By creating the organisation and facilities to encourage this approach it seems realistic that the current balance between expensive residential / nursing care and domiciliary care can be shifted by, say, 20%. The likely savings would amount to more than £100K pa. Further direct savings to Adult Care will accrue from the avoidance of crises which involve expensive interventions.

Overall, it is reasonable that "The Vision of Caring" will lead to savings of between £600K and £750K pa – it may prove to be considerably more – representing something like a 10% financial annual saving on social and health care expenditure. The scheme itself, as shown in the financial model[20], would need an input of about £200K pa to balance the budget. Thus, if we take this figure away from identified savings we can show an expectation of a "profit" of £400K to £550K pa by investing in the scheme (this includes servicing of the capital costs).

More importantly, however, there is every prospect that the "Vision of Caring" model will lead to a step change improvement in the care that is delivered to the elderly. Furthermore, it is believed that current approaches to care tend to lead to the frail elderly being excluded as contributing members of the community. By integrating and embedding their health and social care into the local environment we hope that this trend may be reversed.

The achievement of these benefits arises from drawing together the various strands of care within an umbrella social enterprise. This will facilitate close working of professionals and volunteers in the manner proposed by the "Total Care" approach[18] and the "Enhanced Flexible Domiciliary Care "pilot[19]. It also enables sharing of accommodation, resources and aspects of administration. Overall it may be viewed as a collaboration between the Community, the NHS, and the Adult Care Services. Figure 3 below shows the suggested organisational structure for the scheme.



Note: The Care Quality Commission is expected to have advisory responsibilities at the trust level and regulatory/monitoring responsibilities at the service level.

Figure 3. Organisational Structure of the Integrated Health and Social Care Scheme

Potential for other Communities

The proposed scheme will be a valuable model and an exemplar for application in other rural areas around Suffolk and across the UK. Approximately 51% of the total population of Suffolk reside in rural communities of a similar nature, size and composition to that of Debenham and its surrounding villages. This figure would be significantly greater if calculated in terms of the elderly. Considering this alongside the inherent remoteness of health and social care services in country areas, the authors believe that there is an urgent need to find and pilot "rural solutions". The "Vision of Caring" offers a new and innovative approach for an acceptable, fair and humane level of care. It is a model that could be applied on a county and national scale and which could yield a substantially improved quality of life for the elderly frail at a reduced level of public expenditure.

The authors believe that the approach which is being pioneered by The Debenham Project can spread throughout other rural counties. It is accepted that no other community will be exactly the same as Debenham, but much of the understanding involved in the development of the project will be relevant. Elements and experience may also be of use in more urban environments.

The key aspect of this proposal is the shift from a "service provider" model to one which is firmly characterised by the community adopting responsibility for the care of its elderly frail, and "drawing in" the professional services to meet the need of the individual i.e. the "service provider" becomes the "service supplier" and the "community" becomes the "purchaser" on behalf of those needing support.

The Debenham catchment area is by no means unique – it represents a "cell" within rural Suffolk (and the UK).

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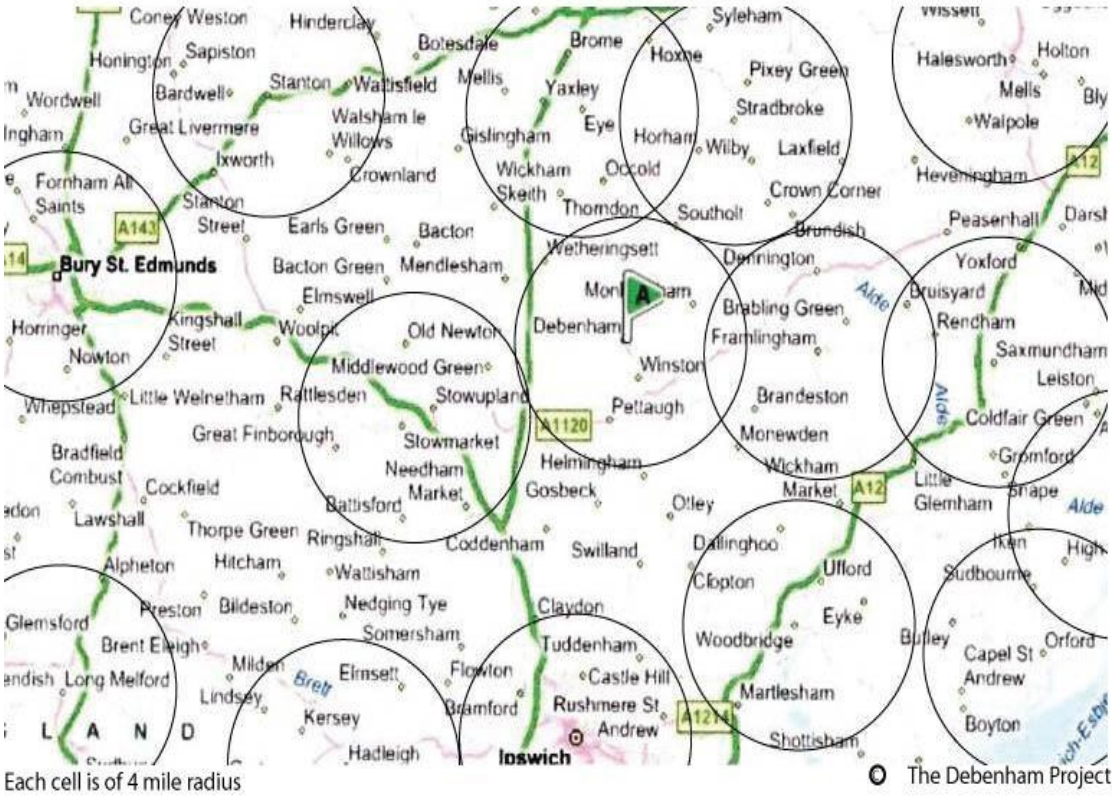
Figure 4.

A possible Cell Structure for Mid & East Suffolk



Each cell is based on a natural centre of population. The above diagram shows that using a "4 mile" model it is possible to achieve good coverage of the rural population.

It is believed that, with a demonstration of the importance and the commonsense of the approach, adjacent geographic "cells" will want to adopt key aspects (I look over the garden fence and see my neighbour has a new Mercedes and I think that I should like one of those!). It is believed that a natural evolution of rural care will follow (but not slavishly) the philosophy and principles of the "Vision". A cellular structure of community-led care schemes across the county and beyond is envisioned. Each cell will have its own particular characteristics determined by the available infrastructure and individual personal skill base. Those cells directly connected to the larger conurbations e.g. Ipswich and Bury St. Edmunds may find that more of a cylindrical structure works better with schemes located around the urban periphery However, given a clear example of what can be achieved it is believed that most communities will respond positively.

The simplistic "possible cell structure" of figure 4 suggest a crude initial estimate of financial savings in excess of £7.0M pa just for those rural communities identified in Mid and East Suffolk. When all factors are taken into account it may be substantially more.

Conclusion

This paper has described an innovative approach to the care of the elderly frail in a typical rural community. It adopts the view that the future for care will be community led and managed. It proposes the possibility that no one should have to leave their familiar community and support network no matter how frail they become – that treatment in hospital should be reserved for only the most serious of conditions and

that hospital stays should be of very limited duration. The paper has shown that it is possible to achieve this by creating an integrated approach to health care, social care, and housing and that this will not only deliver significant improvements in the quality and expectations of life for the individual, but also at a lower cost than can be achieved currently.

The ethos of the project and its objectives are similar to those of "The Swedish Way"[22] in that it is person centred - focusing on the needs of the individual and their continuing importance and involvement in the community. It is also community centred – stressing the importance of active involvement of family carers and local volunteers, and also locally recruited paid carers.

The authors believe that the approach described in this paper is the obvious direction that the provision of health and social care must take.

* Debenham and its surrounding villages to an approximate radius of 4 miles.

** Anyone in the general category of family, friend or neighbour who voluntarily provides a significant amount of help and support on a regular basis – a more formal and precise definition is available.

*** Where it is advisable to maintain an almost constant (24/7) awareness of the well-being of the cared-for, where a more communal hotel-style approach is desired/recommended, or where the person may be being assessed for their needs for supported accommodation.

Acknowledgments

The authors acknowledge that this paper could not present, and argue for, this approach to health and social care without the commitment and support of a large number of people across the breadth of the community and care provision sectors. The goodwill and freely given help that has come from the local authorities (county, district and parish), the NHS (PCT, MH Trust, local GP practice), the charities, all local businesses, and individuals has been remarkable. Without this support The Debenham Project could not have developed in the way, and with the pace, that it has done. As a result the proposal in this paper is not an academic or social dream but a realistic opportunity to produce the model for the next generation for rural care of the frail elderly over the next 25 years. We do not wish to distinguish particular individuals from the many who are an integral part of the inception and continuing success of the project but two names deserve special mention. Firstly, the county councillor for the Debenham area, Eddy Alcock, who presented what we were seeking to do to his colleagues and officers with eloquence and commitment and, by so doing, opened doors to the support that the project needed. Secondly, Alan Reynolds, who as Area Manager, Access and Partnership for Suffolk County Council, recognised the potential of the Debenham Project in its earliest days and has championed its development – this is an exemplar of how local authority / community projects should be managed. In addition we thank Sue Stabb, John Lambert, Karen Wood, and Carole Taylor-Brown for their help in providing statistics and in critically reviewing the concept and its potential viability. To everyone else, and especially those within the project, we can only say "Thank You".

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Lynden graduated in electrical engineering at University College London and spent a long career with BT in electronics and computer software engineering; developing,

leading and managing national and international cooperative research. Upon retiring he trained as a secondary teacher. He was a volunteer for ten years at St Clement's MH Hospital (Ipswich) in the patient's social centre and chaplaincy. Lynden, supported by his wife Sue, was the primary carer for his mother, who had dementia, until she had to go into residential care. He is the chairman of The Debenham Project. He has sought to bring together a belief in "what is right for the community" with Judith's insight and professional experience and so to guide the development of the "Vision" as a model for the next generation of care.

Judith Hawkshaw, MBE

This Model of Care has been developed in large part through the influence of Judith Hawkshaw, M.B.E. who died suddenly on July 30th 2010. Judith has inspired many in Suffolk and nationally over the past 20 years by her vision, drive, commitment and ability to "get things done" for people who need housing, care and support. Her mantra has always been the importance of people having their own front door rather than having to rely on institutional care, local services for local people, and models of care that respect and retain people's aspirations. In this way, she pioneered the development of Very Sheltered and Extra Care Housing. The 24 schemes (along with many other supported housing services for a wide range of people) she developed in Suffolk will be her lasting legacy. Her guiding principle was always (in her blunt Yorkshire approach) "if it's not good enough for my mother, then it is not good enough!" She brought her support and enthusiasm to the development of the Debenham Project's Model of Care, providing invaluable clarity of purpose and the confidence that it is achievable – the Project would like to dedicate this model to her.