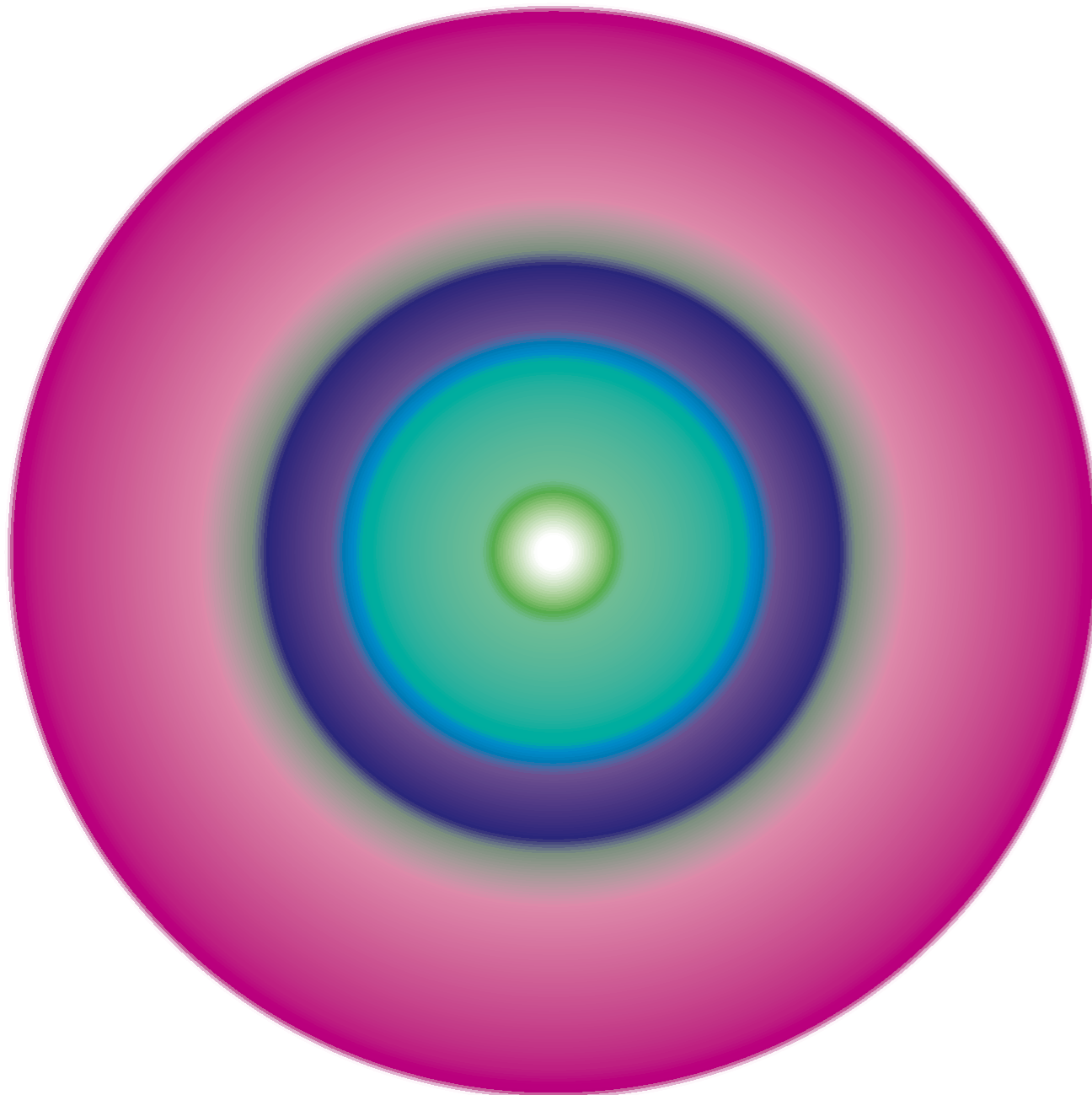




The Long Term Conditions Pathway



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'Living with' not 'suffering from'

1

Our approach to managing long term conditions is fundamentally changing. Many improvements have already been made but these need to go faster and further if we are to meet the challenges of the future – particularly if we are to address the needs of our ageing population. This chapter (based on the work of the Long Term Conditions (LTCs) CPG – full report available at www.yorksandhumber.nhs.uk) sets out what we need to do to improve care for people with LTCs.

2

People want and need to be supported in managing LTCs. Whether they are struck by an acute episode and are seeking to gain control of their lives and reclaim independence, or whether a condition creeps into their lives – it needs to be recognised that people with LTCs are already engaged in that condition as they live with it every day. However, they may still need to be empowered in order to feel confident about the decisions they make about their care and the services they require.

The Case for Change

3

The LTC CPG looked at key issues around the current and growing problem of LTCs and in particular diabetes and stroke within the Y&H region.

Diabetes

4

Diabetes was chosen as a focus of the CPG as an area of concern in the Y&H region. The following data and information gives a snapshot of the issue in support of the case for change.

5

Nature of the condition:

- Diabetes is a chronic and progressive disease that has an impact upon almost every aspect of life. Diabetes is the leading cause of blindness in people of working age in the UK. Other complications may include ketoacidosis, kidney failure and lower limb amputations in later stages of the disease.
- It affects infants, children, young people and adults of all ages, and is becoming more common. There are two types of diabetes, Type I and Type II. Over 90% of people with diabetes have Type II, which is preventable. One of the main risk factors for developing Type II is obesity.



6 Impact on Y&H population:

- 25% of men and 24% of women in Y&H are obese.
- This is predicted to rise to 28.8% and 28.5% by 2010 (784,000 men will be obese) - see Figure 21.
- Two thirds of the increase in Type II diabetes is the result of obesity.
- Lower limb amputations are significantly higher in North Yorkshire than the national average.
- Within Yorkshire and the Humber, emergency admissions due to diabetic ketoacidosis (the medical term for diabetic comas) are twice as high in some areas compared to others.

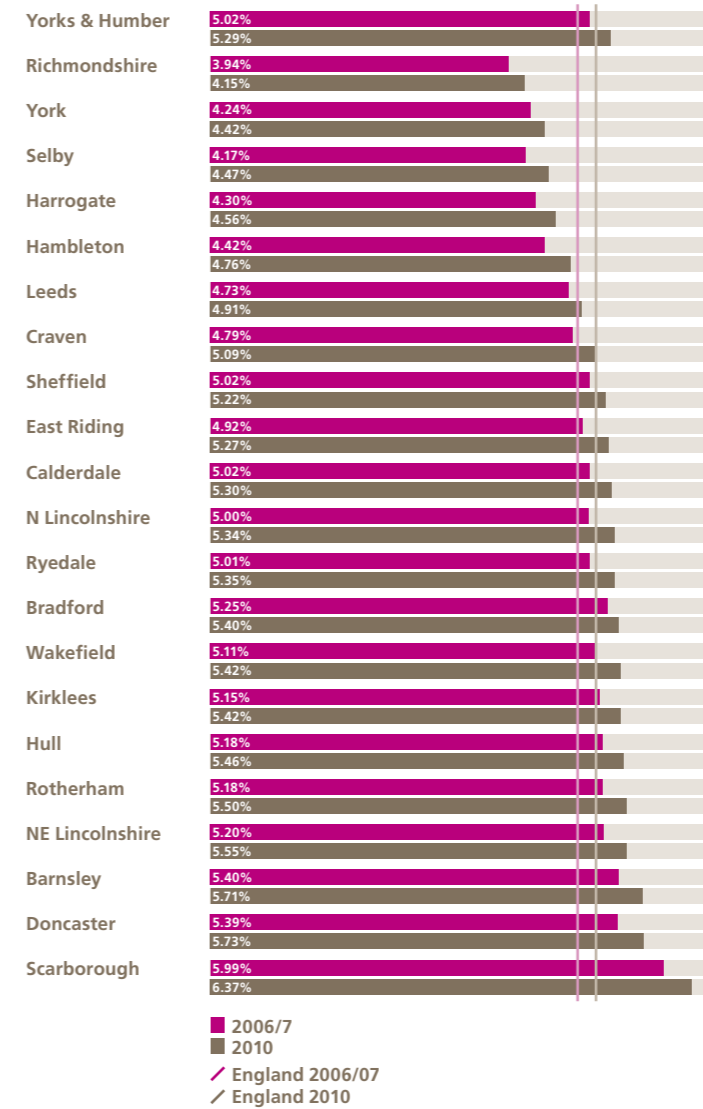
7 The SHA recognise the rising concern over this condition and want to reduce every year the number of diabetic patients under 65 years of age who suffer blindness or amputations.

8 There are a number of issues about young people and the diagnosis and management of diabetes.

- Diabetes UK has recently published research showing how the number of under-fifteens with Type I diabetes had doubled over the last twenty years.
- Diabetes UK survey 'Your Local Care 2005' found that only a quarter of PCTs made paediatric diabetes service improvement a priority.
- A 2007 Department of Health report "Making Every Young Person with Diabetes Matter" refers to evidence that 85% of young people do not have adequate blood glucose control.
- Lifestyle issues including sport, binge drinking and body image contribute to poor management of insulin/food intake.

9 Young people therefore may need support and engagement using a different approach in encouraging them to manage their Type I diabetes.

Figure 21. Diabetes Prevalence in Y&H in the next 3 years is set to increase substantially



Stroke

10 Stroke was chosen as another focus of the CPG as an area of concern in the Y&H region. The following data and information gives a snapshot of the issues in support of the case for change.

11 Nature of the condition:

- Strokes are a blood clot or bleed in the brain, which can leave lasting damage, affecting mobility, cognition, sight or communication. Adverse lifestyle is the biggest risk factor for the onset of stroke.

12 Impact on Y&H population:

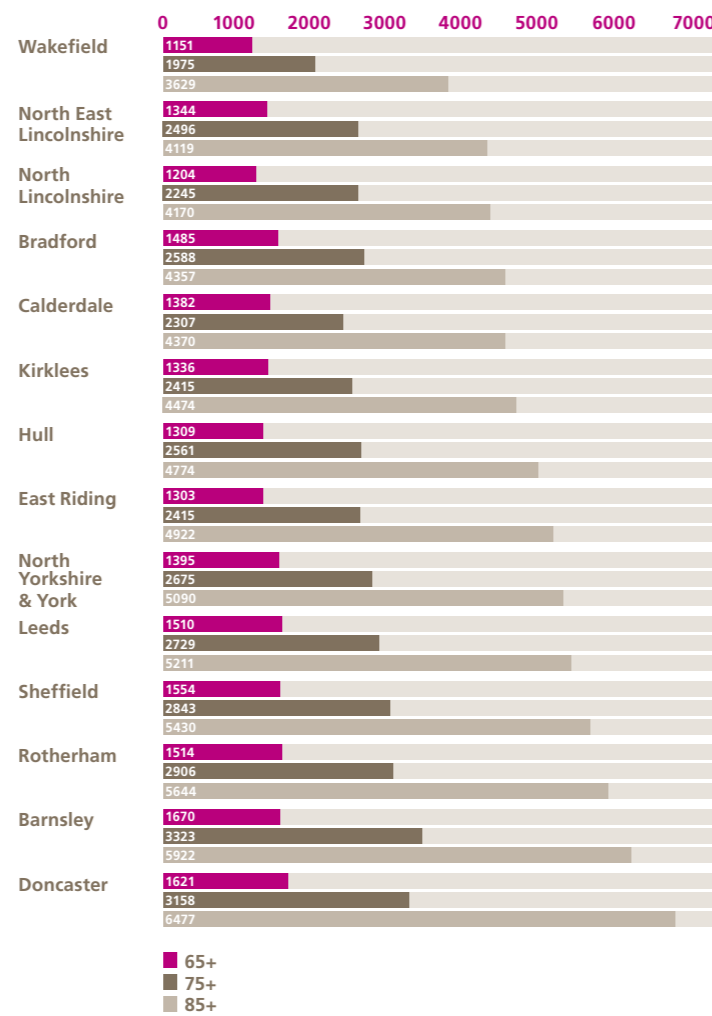
- 9 of the 14 PCTs in Y&H diagnose more strokes than the national average.
- Registered prevalence ranges from 1.4% in Hull to 2.1% in Rotherham and Doncaster – the national average is 1.6% (based on 2005/06 QOF data).
- Stroke mortality remains an issue.

13
The SHA want to address the issue of premature death by stroke and are aiming for 3,000 fewer people p.a. in spearhead PCT areas to die from stroke before the age of 75 by 2010. Management of acute stroke is addressed in the chapter on acute episodes.

Old Age, Frailty and LTCs

14
As a third area, the CPG focused on frail older people, as they often have multiple conditions and their frailty adds extra complications, which prevents them from being fully mobile and able to properly self care. Frail elderly people tend to experience frequent and lengthy hospital stays.

Figure 22. As people get older they become more frail, resulting in more hospital admissions / Source: Hospital Episode System (Department of Health)



15
The following data and information gives a snapshot of the issues in support of the case for change:

- Age is the most significant driver of prevalence of LTCs.
- More than 70% of those over 75 have one or more LTC compared with 20% of the 16-44 year-old age group.
- The probability of having multiple LTCs increases with age.
- The probability of older people having falls and accidents also increases with age.
- Falls are a common reason for older people to be admitted to hospital (see figure 22).
- Hip fractures account for 50% of injury related admissions and 66% of bed days for over 75s, often caused by fragility and low impact fall.
- Loss of confidence, fear of falling and subsequent loss of independence are other important consequences of falls.

Key Recommendations

16
Care Plans – through a co-produced care planning approach, patients and their carers should be supported, informed and empowered to better manage their condition within their capabilities and enabled to make choices about their care and services. Those who are newly diagnosed should be offered a care plan at the outset.

17
Care Choices – Patients should be offered choice following the ‘Choice and Personalisation’ model approach, which is patient centred and takes into account lifestyle factors. This will allow services to be designed and commissioned, allowing patients the independence of choice throughout their contact with services, including residential, intermediate, outpatient and hospital based care.

18

Year of Care approach – Commissioners and providers should define patient pathways based on the two models referred to in this report. For example, this should be reflected in a programme of work to roll out excellent stroke services, in line with the National Stroke Strategy recommendations. Diabetes services in particular should be developed using emerging learning from the Year of Care pilots. Both models are exemplars for further work in other LTCs.

19

Care Conductor – a role should be developed to help with the management of care for people with LTCs, their families and carers and ensure care plans and care choices are co-produced for better outcomes.

20

Coordination – Primary care should remain the hub of coordinating and managing care outside hospital for people with LTCs. Practices should support individual health to improve population health.

21

Commissioning – Practices and PCTs should commission services based on quality clinical information. Where there are variations, robust monitoring should be used to challenge the quality of disease registers and improve case finding.

- Joint commissioning, joint strategic needs assessments (JSNA), Local Area Agreements and practice based commissioning should be fully exploited in order to design and develop services which reflect the standards, the choices of patients and the clinical and professional knowledge within health communities.
- The use of incentives and/or penalties should be explored to improve better quality information and better commissioning.

22

Integration and partnership working – Commissioners and providers should work in an integrated way to better support delivery of patient pathways, for example:

- Services such as Intermediate Care that support primary and secondary care, should be speedy, responsive and work with case management.
- Specialist Clinical Services (particularly for stroke) and comprehensive geriatric services need to be further developed to meet the needs of the growing elderly population.
- There should be a collaborative approach to voluntary, health and social care sector planning.



23

Care Standards – A common set of standards should be developed to support and standardise care delivery. These should be applicable in all settings, including primary care, secondary care and in particular to ensure quality of care in nursing and care homes.

24

Core Competencies – A core set of competencies should be developed for patients, carers and staff, aligned with the above care standards so individuals and organisations know what to expect from quality service and care provision. These will also help facilitate any shift in behaviours and culture.

25

A key proposal for reforming adult social care (Department of Health's Transforming Social Care Local Authority Circular January 2008) is to give personal budgets to all people receiving social care services. There is scope to see if this could be extended into some aspects of health care also.

26

In order for these recommendations to become reality, it is vital that support is given to providing the necessary joined-up IT, information, premises and trained workforce. The CPG members understand these will be national priorities.

The Long Term Conditions Pathway

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The CPG identified two key models, which fit with the vision for delivering care that is personalised, and which offers choice within a year of care approach, driven through excellent commissioning:

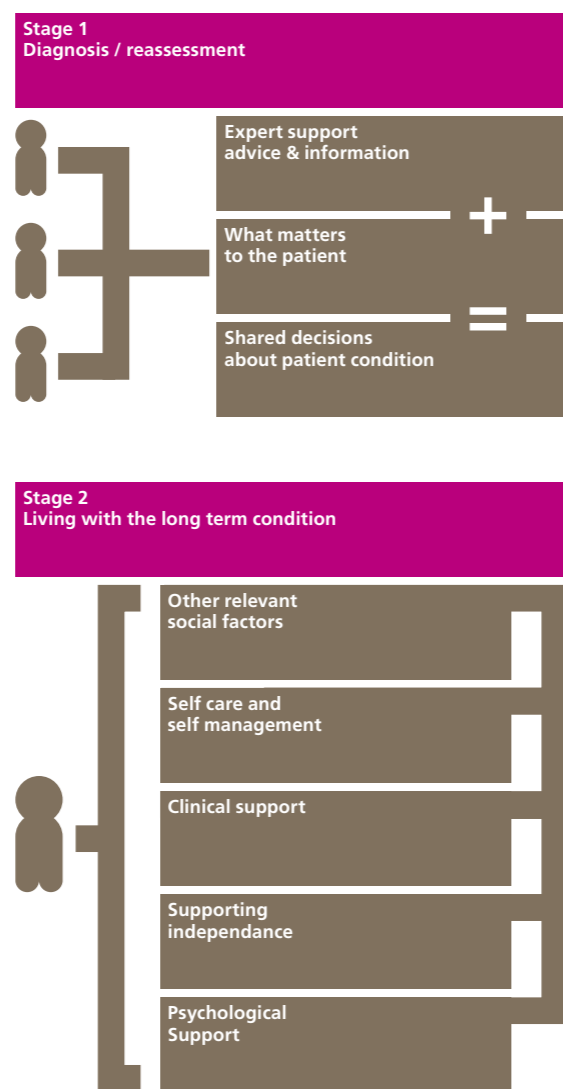
- The "Choice and Personalisation of Care" model for Commissioning.
- The 'Year of Care' Model pathway for designing and delivering care.

28
The 'Year of Care' planning model is a generic clinical pathway for the management of LTCs. The CPG felt this was sufficiently comprehensive and was a best fit with their clinical aspirations. It requires only minor modifications in order to offer equal benefit for most, if not all, LTCs. The following is a typical Year of Care pathway for a patient with diabetes.

29
Both models represent the CPG's views that future services should be commissioned and configured to maximise for individuals and service users their:

- Independence
- Choice
- Control

Figure 23. Choice and Personalisation of Care model
Source: Operating Framework 2008/9. Dept of Health 2007



Choice of where/whether to receive treatments or services.
Choice of whether to receive single or group services.
Access to practical information on options, risks, benefits, treatment lifestyles, behaviours mgt etc.

Figure 24. A Patient's Journey / Service Pathway
Source: Diabetes NSF. Dept of Health 2002



**The Pathway in Practice
Empowering Patients**

30
An excellent service where patients are empowered can be a key lever and would include the following characteristics, listed below.

31
People with LTCs and their carers would be encouraged to be more involved in the services they receive for their condition. This requires providing information and education about the condition, about services available and about care options, bearing in mind that people learn in different ways.

32
Information about LTCs should be in a nationally standardised (PDF) format available in different languages and formats and should be marketed through the media.

33
This can be reinforced by making generic education (Expert Patient Programme) or 'buddying' schemes more widely available to users and carers and by providing disease-specific education and self management programmes e.g. DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed) and DAFNE for type 1 (Dose Adjusted for Normal Eating and Newly Diagnosed). Patient empowerment methods and education programmes need to take account of language and cultural issues.



34

As pilots are evaluated and more evidence becomes available, 'direct payments' or personal budgets should be explored, enabling people with LTCs to buy in the care and support they need from the most appropriate and available resource.

Prevention

35

The CPG for long-term conditions fully supports the recommendations set out in the 'Staying Healthy' chapter in addressing the key issues of obesity, smoking, alcohol and drug abuse. Cultural differences must be considered as these are central in the development of many long-term conditions. It is recognised however that not all long-term conditions are preventable.

36

Once diagnosed, further deterioration of the condition and promotion of well-being should to be incorporated into every care pathway as key components of care. These should be subject to regular review.

Screening

37

Screening for long-term conditions is closely linked to prevention – particularly in the case of Type II diabetes – but needs to be applied selectively, backed by reliable evidence about the impact of early detection.

38

Organisations should demonstrate the use of predictive modelling and case-finding tools such as the King's Fund's 'Patients at Risk of Re-hospitalisation', to analyse population need and establish levels of risk within particular groups. This will enable resources to be targeted to achieve maximum health outcomes.

39

Information from other screening sources that never reaches the NHS information systems could be used, such as data from occupational health schemes.

40

A greater emphasis needs to be placed on screening 'hard to reach' groups, especially those not registered with a GP. This also applies to vulnerable sections of the community, such as people with a learning disability.

41

A national accreditation process or kite mark should be established that informs patients about the standards of care they should expect and the arrangements in place to monitor them.

Diagnosis

42

A 'world-class' service should be driven by nationally-approved and applied diagnostic criteria and protocols. Primary medical services should be bound by NICE guidance.

43

Work is needed in order better to understand the cost effectiveness of a greater use of mobile diagnostic services to reduce the emphasis on hospital-based diagnosis. An extension of training for health professionals to heighten awareness about medication for patients with multiple and complex conditions is also crucial.

44

Primary care medical contracts should underline the central role of GP practices in the identification, diagnosis and treatment of people with long-term conditions, supported by specialist advice and input.

Post-diagnosis management

45

Care of long-term conditions should be personalised, with maintenance of dignity, independence, self management and choice embedded at its core.

46

People with long-term conditions should be encouraged to be more proactive about their condition and the services they receive. This requires education about their condition, the services and assistive technology available to them and the care options.

47

Nationally-directed public and media education is needed to change perceptions about elements of care services, so that for example, a patient begins to see that, with the right support, some hospital admissions could be avoided, and that this is beneficial to their health.

48

Social marketing is a powerful instrument of changing a culture of dependence on the NHS. Its effect will be intensified by the availability of generic education and self management programmes as well as others focused specifically on one condition like DESMOND (Diabetes Education & Self Management for Ongoing and Newly Diagnosed) and DAFNE for Type 1 Diabetes (Dose Adjusted for Normal Eating and Newly Diagnosed).

49

Person-centred care also means consideration of mental capacity and forward planning for End of Life care including establishing powers of attorney and living wills so that families and carers are better prepared to exercise choice.

50

Telephone help lines could be available 24 hours a day for patients with a pre-existing condition, where changes in their condition can be discussed, rather than dialling either NHS Direct or 999. Help lines could be accessed via a single national or regional telephone number.

51

More work is needed to reduce the number of patients failing to attend hospital appointments by increasing use of text reminders.

“A significant benefit is having one record that 70% of GPs in Bradford and Airedale can see instantly. Clinicians can now automatically see everything that’s been added to the record and the immediacy of information is impressive.”

Barriers to Change

52

The CPG highlighted the fact that now many ‘young’ older people are caring for much more elderly people. Some suggested that the option to extend working lives beyond 60, where desirable, should be explored. Carers and neighbours should be encouraged, supported, trained and paid where appropriate, with mechanisms to give them easy access to specialist help for guidance.

53

‘Expert carer’ programmes are needed to complement ‘expert patient’ programmes.

54

Services need to ensure that standards applied to the general population with respect to prevention, diagnosis and treatment are applied equally to hard-to-reach groups such as people with a mental illness. Offender health (particularly in relation to older prisoners) is a service area facing increasing demand (see Department of Health October 2007 – ‘A pathway to care for older offenders: A Toolkit for Good Practice’).

Good Practice

NE Lincolnshire Care Trust Chronic Obstructive Pulmonary Disease Service

Description:

- Regular attenders at A&E and people admitted through the COPD service were identified.
- They received training and support through ‘buddying’ with other patients identified as managing their condition effectively, who had previously received training from specialist nurses.

Links with other services:

- The service is PCT-wide and supported by GP practices.

Results:

- Hospital admissions and A&E attendances have dramatically reduced for the identified group of patients.
- The training has been successful for patients in supporting self-management.

Sources

1

This chapter is based on the work of the Yorkshire and the Humber Long Term Conditions Clinical Pathway Group. Report available at www.yorksandhumber.nhs.uk. Membership of the group is shown at Appendix 1.

2

Yorkshire and Humber Focus Group Reports – September and December 2007.

3

National Stroke Strategy

Sources

4

‘Our Health, Our Care, Our Say’ White Paper

5

LTC National Service Frameworks (NSFs)

6

NHS Yorkshire & the Humber Health Blueprint, June 2007

7

Dr Foster

8

Diabetes UK ‘Your Local Care 2005’

9

‘Making Every Young Person with Diabetes Matter’, DH

10

GOYH website www.goyh.gov.uk

11

Is the NHS becoming more patient-centred?, Picker Institute Europe, September 2007

12

‘A pathway to care for older offenders: a toolkit for good practice’, DH, October 2007

13

King’s Fund ‘Patients at Risk of Re-hospitalisation’

Yorkshire & Humber Long Term Conditions Diabetes Programme

A National Programme for IT pilot project – sponsored by the National Clinical Directors for Diabetes and Children and led by the SHA – aims to transform the care planning aspirations defined by the ‘Year of Care’ work into a reality using TTP SystemOne. This is currently used by 288 GP practices in Yorkshire & the Humber. The TPP system is flexible and through a shared health record that is integrated to Connecting for Health products, it can bring patients together with a team of professionals from primary, secondary and social care, from public health and from other healthcare professions. If the diabetes pilot is successful, it could also be relevant to all long term conditions.

The pilot is progressing with a cohesive review of ‘cradle to grave’ diabetes services covering providers in the region, based on enabling information flows for patients across the care pathways through primary, secondary, community, child health, social care.

The aim is to reduce complications, improve outcomes, and reduce unplanned admissions.

Conclusion

55

With nearly 1.5 million people in Y&H predicted to be living with some kind of long-term condition by the end of the next decade it is clear that there is a big challenge ahead – not just for the NHS, but all those involved in supporting individuals and their families and carers.

56

The CPG have highlighted the importance of accelerating the personalisation of care, giving individuals the tools – physical and mental – to have much greater control over their own health. We are already making a start, with many examples of excellent practice, but over the next decade we need a step change in our own attitudes and approach to this area of health.

57

Our pledge in taking forward this pathway will be to half the number of preventable admissions from diabetes.