Scrutiny Report

Health Scrutiny Panel

Ensuring Effective Continence Care

October 2013

NORTH LINCOLNSHIRE COUNCIL

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GLOSSARY

Term	Description
A&E	Accident and Emergency
APPG	All Party Parliamentary Group. A cross-party group of Parliamentarians set up to investigate a specific topic of concern.
DPoW	Diana Princess of Wales Hospital
GDH	Goole District Hospital
GP	General Practitioner
HCAI	Healthcare Acquired Infection. A range of infection types acquired as a result of medical intervention..
LUTS	Lower Urinary Tract Syndrome — a range of conditions related to problems with urination.
NLAG	Northern Lincolnshire and Goole NHS Foundation Trust. The local provider of acute and community care.
NLCCG	North Lincolnshire Clinical Commissioning Group. The NHS organisation responsible for designing, developing and buying local health services in the North Lincolnshire area
NLPCT	North Lincolnshire Primary Care Trust. NLCCG's predecessor commissioning body.
PCTs	Primary Care Trusts. A former localised organisation responsible for commissioning healthcare.
SGH	Scunthorpe General Hospital
UI	Urinary Incontinence. A medical condition characterised by the involuntary leaking of urine.
UTI	Urinary Tract Infection. An infection of the upper or lower urinary tract.

FOREWORD FROM THE CHAIRMAN

Continence issues are very common. It has been estimated that around 14 million people in the UK have some form of problem with their bladder; more than the number of people with asthma, diabetes and epilepsy put together. Despite this prevalence, it is a subject that receives very little attention in the nation's psyche. There is a reluctance to discuss incontinence, which can lead to poor service provision. From an already low base in 2007, a follow-up survey in 2012 by the All Party Parliamentary Group (APPG) found that services across the country were under increasing pressure as demand has significantly escalated whilst budgets have remained static at best, waiting times have increased, and staff morale suffers. In some areas, services are not promoted for fear that this will increase referrals and the APPG warn that, increasingly, people are simply likely to be referred into a rationed 'pad service.' Despite this, many forms of incontinence are curable or can be improved or managed simply, cheaply and effectively.

Anyone can develop a continence issue, at any stage of their lives. For many, they will choose not to discuss it with their family or their GP, they will suffer alone, and it is likely that they will withdraw from everyday social activities that they may have previously enjoyed. Their social isolation will increase, as will their likelihood of an avoidable admission to a hospital or a residential care home.

This review looked at services in North Lincolnshire. Our findings largely reflected the national picture described above. Despite the best efforts of the front-line practitioners and their management, services are struggling with rising demand and static budgets. We know that demand will continue to rise significantly in the coming years as the population increases and ages. At some point, if the current model continues, services will become unsustainable. We believe a review is required, taking into account the views of commissioners, providers and service users. Funding can be made to work harder by looking towards preventative work, and by ensuring patients can receive early treatment instead of being prescribed a lifetime's supply of pads. There is a wealth of guidance, best practice and recommendations from a Needs Assessment available. All that is required is for the various parties to sit down to work through these and ensure that services are in place and joined up. Quite rightly, the government has stated that patient dignity is a key priority for the health service. This is a clear opportunity for local NHS leaders to demonstrate that they too are focussing on ensuring the dignity of our local population.

I would like to thank the Vice-Chair, the members of the scrutiny panel, and the witnesses we spoke to for their invaluable input.

Councillor Jean Bromby
Chairman of the Health Scrutiny Panel

RECOMMENDATIONS

It may be reflective of the low profile that continence issues receive that a series of achievable, practical and specific recommendations were part of the 2001 Needs Assessment. Despite the fact that these were made some 12 years ago, and were often based on data two years older than that, they remain relevant to this day. The panel has decided to update and reiterate these recommendations, whilst also including our own recommendations for making improvements. The Needs Assessment concluded that services needed to improve, based on the following principles. The panel believes that these also remain relevant.

The service now needs to:

- Develop a clear strategic direction;
- Include the expertise of service users and carers in planning, providing and monitoring of the service;
- Develop practice guidelines;
- Raise the profile of the service;
- Raise levels of continence awareness amongst practitioners and the public; lack of awareness contributes to a mindset that considers management of incontinence rather than prevention, promotion and treatment;
- Extend training for health and social care staff;
- Improve information about those receiving the service;
- Develop quality assurance, service monitoring, and user-focused outcomes.

Recommendation 1
That North Lincolnshire CCG, in co-operation with Northern Lincolnshire & Goole NHS Foundation Trust and others, lead a piece of work to implement, assess and assure or update the following original recommendations from the 2001 Needs Assessment, reporting to their respective Boards.

1. A multi-agency Continence Service Group, representative of all interests including service users, is set up to guide the future development of an integrated continence services. For example, the Ulster Community and Hospitals Trust established such a group. Consultants, GPs, patients and carers, nursing staff and other disciplines meet quarterly to discuss and revise procedures and set outcomes, which are then reviewed by the group.

An integrated service would include primary and community care, a continence advisory service, hospital services, and access to specialist centres. It would embrace all the health and social care disciplines that are involved in delivering continence services, and cover services to adults and children, in their own homes and in residential settings.

2. The Continence Service Group oversees the development and regular review of care pathways to ensure that people with continence problems gain access to the appropriate level of care for their clinical need, and that care is:

- Consistent,
- Evidence/consensus based,
- Effective.

3. Continence care forms part of a care plan for each individual, and all agencies work to the same guidelines for prevention, promotion, treatment and management.

4. The Continence Services Group works with health promotion colleagues to develop a public awareness strategy that will reduce the stigma attached to continence problems and increase awareness and use of local services.

5. In order to reduce the potentially increasing numbers of people likely to need continence services in the future, a preventive strategy should be developed.

Those practitioners who are best placed to promote preventive action (midwives, health visitors, school nurses, for example), need to be aware of the role they can play.

6. Options to increase access to the service are considered. (For example, a continence resource centre, drop- in clinics in non-stigmatising venues, advertised direct-line telephone contact numbers, telephone help-lines). Arrangements are made to target groups identified as having difficulty in accessing continence services.

7. A key debate is whether continence care should be a specialist service or everybody's business. We conclude that 'ownership' of continence services should be widespread.

Identification of continence problems, initial assessment and first-line management should take place within the Primary Health Care Team (as Department of Health Guidelines suggest), on the grounds that:

- Continence problems are common;
- Access to services could be improved;
- Acceptability could be increased;
- Specialist services can be stigmatising;
- Primary care settings can provide an available source of advice and ongoing support/motivation.

8. First-line treatment within primary care needs to be supported by designated practitioners with additional specialist training. This should include specialist physiotherapy expertise. Expertise in sexuality and continence problems, and in men's health (and male continence advisors) would help to meet needs that are not currently being addressed as well as they might.

9. All individuals with continence problems should undergo an assessment that provides adequate information to allow them to receive appropriate care, including referral where more specialist investigation or intervention is required.

10. To ensure that individuals are assessed adequately and consistently there should be compulsory training/standardisation for all staff who would carry out assessment at primary and secondary care levels. Regular audit of assessment would help to ensure ongoing quality.

11. People in residential settings should have access to the same level of service as those in the community. Training and support opportunities should be extended to all those providing residential care.

12. A regular programme of recorded training is required, so that relevant staff are

systematically trained and updated, in order to provide a consistent, high quality standard of service. Training needs are greater than the continence advisors alone could meet. Their role might be to work with training departments to develop, for example, basic awareness training that could be delivered by others.

13. The continence service provided to hospital patients and their relatives, including assessment, arrangements prior to discharge, and the training needs of hospital staff, are reviewed.

14. Practice in use of catheters on hospital wards is investigated and reviewed with a view to developing guidelines for use of catheters, their removal and re-establishment of continence before discharge, and the training needs of staff.

The Royal College of Physicians has produced a facility audit of urethral catheter use based on good practice guidelines.

15. The use of peer and group support is investigated.

16. Information requirements are reviewed, so that , for example, a profile of those using continence services, measurement of outcomes, and so on is practicable.

17. Routine audit is built into the process of providing the service.

Recommendation 2
The panel recommends that the proposed CCG-led multi-agency Continence Service Group also audit local performance against the recommendations within the National Audit of Continence Care (2010) and the All Party Parliamentary Group for Continence Care's report "Cost-Effective Commissioning for Continence Care", taking appropriate action to implement any actions not in place.

Recommendation 3
Similarly, The panel recommends that the proposed CCG-led multi-agency Continence Service Group also audit local performance against the recent revised NICE guidance on urinary incontinence (NICE clinical guideline 171).

Recommendation 4
The panel recommends that the proposed CCG-led multi-agency Continence Service Group explore options for implementing a programme of training and support (including on-line training) for care home and nursing home staff.

Recommendation 5
The panel recommends that North Lincolnshire Clinical Commissioning Group:

(i) conducts a thorough assessment of current and likely future demand on the service, including financial costs

(ii) compare the current and future demand against capacity, and

(iii) take appropriate action when commissioning services for 2014/15 and into the future.

Recommendation 6
That Northern Lincolnshire & Goole NHS

Foundation Trust's Medical Director and Chief Nurse explore the costs and benefits of designating a specialist continence nurse at Scunthorpe General Hospital, to lead on actions to reduce unnecessary catheterisations, forging links between primary, community and acute care, and joining up continence care across specialties such as urology, gynaecology, geriatric medicine etc.

The panel acknowledges that priorities and workstreams for 2012/13 are agreed and are well underway, but would wish to see the above recommendations acted upon early within the 2013/14 commissioning cycle. As such, the panel will request a detailed action plan responding to each of our recommendations approximately six months after publication of this report.

FINDINGS

Few health issues are as common as bladder and bowel dysfunction, that can have such a profound impact on a person's wellbeing, privacy and dignity, yet receive such a low profile amongst the public and some health and social care organisations. There are deep-rooted cultural reasons for this lack of attention. Many people find it difficult to discuss continence issues with anyone, including those in the health services who are in a position to assist. This can lead to people isolating themselves from others, not seeking relationships or friendships, and withdrawing from social contact.

However, urinary incontinence is the symptom from an underlying cause. National guidance states that "incontinence can be cured, symptoms reduced or appropriately managed by a wide range of aids." The routine provision of products should never be the primary focus of treatment.

A national audit of continence care in 2010, found a host of failings, both at operational and clinical level. Services across the country are typically poorly integrated across settings, often resulting in disjointed care for patients and carers. The overall findings of the audit state that:

"People of all ages, and vulnerable groups in particular (frail older people, younger people with a learning disability) continue to suffer unnecessarily and often in silence, with a 'life sentence' of bladder and/or bowel incontinence".

Source: Royal College of Physicians, London

Often seen as an older people's or pregnancy related issue, continence issues can affect men, women, young people and children of all ages. It can be related to illness, maternity, injury and disability, or it can occur in people in generally good health. Urinary incontinence alone has been estimated to cost the NHS some £117 million a year[1] .

It is difficult to assess the prevalence rate amongst the general public, due to a lack of a standardised methodology, plus the reluctance to discuss that was highlighted previously. However, a range of studies suggest that between 25 - 45% of adult females will experience some level of urinary incontinence (UI)[2] at some stage within their lifetime, around a third of older (50+) men will have at least one Lower Urinary Tract Syndrome (LUTS) symptom[3], and between 50 - 80% of care and nursing home residents will experience UI and / or faecal incontinence[4]. NICE guidance on UI suggests that commissioners use a population benchmark of 0.80% of the female adult population as a benchmark for referral into the continence service[5].

In 2001, the former South Humber Health Authority published a Needs Assessment estimating the number of Northern Lincolnshire residents with incontinence. Using data from 1999, this estimated that between 11,632 and 13,682 adults had some form of incontinence[6]. The assessment didn't include children and young people, or those with a continence issue that didn't include

1. Imamura M, Abrams P, Bain C, et al. Systematic review and economic modelling of the effectiveness and cost-effectiveness of non-surgical treatments for women with stress urinary incontinence. Health Technol Assess. 2010 Aug;14(40):1-188, iii-iv.
2. Abrams, P., Cardozo, L., Khoury, S., Wein, A. (Eds.). Incontinence (4 ed. pp.1767-1820). Health Publications Ltd.
3. ProState of the nation report 2009: A call to action: delivering more effective care for BPH patients in the UK. GlaxoSmithKline, 2009.
4. Schnelle JF, Leung FW. (2004) Urinary and faecal incontinence in nursing homes. Gastroenterology. 126;Suppl 1:S41-7
5. National Institute for Health and Clinical Excellence, Urinary Continence Service — Commissioning and Benchmarking Tool, 2010.
6. Community Continence Services for Adults in the South Humber Health Authority Area , April 2001, South Humber Health Authority.

incontinence (i.e. many symptoms of Lower Urinary Tract Syndrome (LUTS))
A 2012 survey of all PCTs by health policy consultancy MHP Mandate found that 95% could not give a robust estimate of the number of people in their area with continence issues. For illustrative purposes only, a general estimate of some continence issues has been attempted by the panel, which should not be used for commissioning or planning purposes. This suggests the following prevalence as an approximation.

Table 1: Estimated Population Prevalence Of Continence Issues in North Lincolnshire.

Condition	Gender (if relevant)	Population	Likely prevalence	Number of people who may benefit from treatment
UI	Female	Circa 85,400. Circa 68,320 adults.	35 % (+/- 10%) of adults[2].	Circa 23,900 females (all ages, +/- 7,000). Given an estimated 50% seeking help[7], this equates to between 8,500 and 15,000 in contact with their GP.
LUTS	Male	Circa 82,000 Circa 65,600 adults.	35% of men aged 50+, with a lower percentage amongst younger men[3].	There are circa 31,550 males over 50 in North Lincolnshire. Given a prevalence level of 35%, this equates to 11,000 men with LUTS. Incorporating men younger than 50 with LUTS, this figure is likely to increase to above 12,000. It is difficult to assess the number in contact with their GP. NB — urinary incontinence is only one symptom of LUTS and may affect between 2,000-6,500 adult men.
UI and /or faecal incontinence	Both genders — care home /communal establishment residents	2,600	50 — 80%[4]	Estimates vary from 1,300 to 2,080 people.
People with moderate / severe learning disabilities	Both genders	3,300 with moderate learning disabilities. 600 with severe learning disabilities	'High' prevalence. 50% for illustrative purposes here.	Illustrative estimate of 1,950 people.
Bedwetting / soiling	Both genders		Bedwetting — 9-22% for boys aged 7-9, 5-10% for girls Soiling — 2.4% for boys aged 7, 0.7% for girls	There are circa 18,900 children and young people aged between 5 and 14 in North Lincolnshire. Circa 850-2,100 boys and 475-950 girls are likely to wet the bed at ages 5 and above. Circa 225 boys and 65 girls are likely to soil the bed at ages 5 and above.

7. All Party Parliamentary Group for Continence Care (2011) Cost-Effective Commissioning for Continence Care.

This estimate suggests that there are at least 35,000 individuals within North Lincolnshire who will experience a continence issue in their lifetime, or more than one in five. Urinary incontinence is likely to affect at least 20,000 people, or around one in 8.5, and it could affect up to 40,000. It is highly likely that this prevalence figure will increase notably over the next 20 years, as the population rises, the number of older people increases markedly, and the number of people with severe learning disabilities also rises.

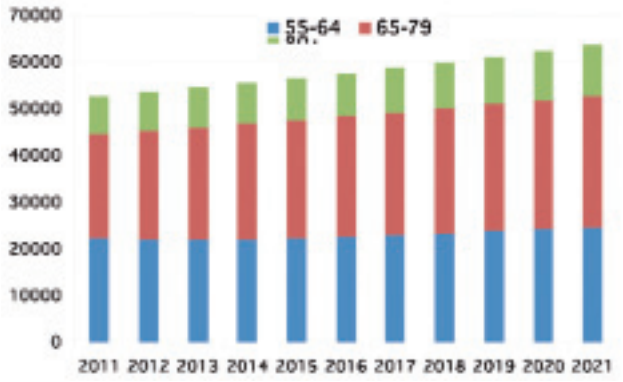

Figure 1: Projected growth in people aged 55+ in North Lincolnshire 2010-2021

Despite this, it is important to note that, whilst prevalence rates do increase with age, symptoms do not necessarily become worse. For example, prevalence of urinary incontinence in females increases from age 20-50, but tends to level off after this. There is a danger of seeing incontinence as inevitable or a normal aspect of ageing, and this can then lead to people not seeking help or investigation and treatment not being considered.

Current specialist provision

An integrated continence service has been established for many years, treating both adults and children and young people. The service is provided by a specialist team employed by Northern Lincolnshire and Goole NHS Foundation Trust (NLAG), working in the community. There are referral pathways in place to specialist consultants and surgeons based locally. Currently services are focussed on treatment, as there is little scope to work with others around prevention, due to limited staffing.

As part of the treatment provided, the service is also responsible for managing the provision of continence products (e.g. pads). Currently, the number of people receiving products via the service stands at 1,716 individuals. This is split between 1,168 people who live in their own homes, and 548 individuals who live in care/nursing homes or other specialist accommodation. It is likely that many people purchase their own products and remain unknown to the service.

The service is made up of two part-time registered Continence Nurse Specialists and one part-time Health Care Assistant, amounting to 1.09 Whole-Time Equivalent (WTE), supported by 0.69 WTE support staff. One of the registered continence nurses is classed as a Clinical Nurse Specialist, and is 0.69 WTE. Guidance from the All Party Parliamentary Group for Continence Care recommends that, at a minimum, there should be one WTE specialist practitioner per 100,000 population. The 2011 census states that there were 167,446 residents in North Lincolnshire, meaning that current provision is less than half of the minimum standard.

The cost of providing products has been increasing year-on-year for some time. Prior to the service transferring to NLAG in 2011, North Lincolnshire Primary Care Trust

(NLPCT), as the former provider and commissioner of services, attempted to take a number of actions to manage the spend within the budget. This included adopting a "three out – one in" model, which inevitably led to an increased waiting list. Since the transfer to NLAG, managers have taken further steps to address the rising waiting list by reallocating underspends elsewhere into the continence service budget. However, this reallocation was limited to 2012/13, and since the start of the new financial year the waiting list has again started to build. At the time of drafting this report, there are 42 individuals awaiting their first delivery of products following assessment, with the longest wait having been since 1 May 2013.

NLAG managers have provided benchmarking information which compares the expenditure against other comparable Trusts. This has demonstrated that the service has maximised value for money (e.g. when comparing cost per patient per day).

Treatment elsewhere in the NHS

Continence issues are likely to make up a small but significant proportion of any GP's daily work, with estimates that continence issues account for between 1-2% of NHS spending. Some people will be able to be treated or advised by the doctor or other clinician, but some will require referral to the continence service or to a consultant or senior doctor, generally at one of the sites at Northern Lincolnshire & Goole. A typical referral will be into the continence service. The guidance is clear that people, wherever they present within the NHS, should be fully assessed and all options should be explored, and that individuals shouldn't "just be sent for pads".

For a host of reasons, other people will be admitted directly to hospital for a range of related but more serious conditions, such as urinary tract infections (UTI), urinary retention, renal failure, pressure ulcers and faecal impaction. This could be via their GP, via A&E or through any other route. In 2012/13, local A&Es treated 1,890 individuals for such conditions, admitting 546 to a ward.

Inappropriate catheterisation remains an issue across the health field. It has been estimated that catheters are used inappropriately in around a quarter of cases[5], with catheters leading to 60% of catheter associated urinary tract infections (CAUTI). Research suggests that nurse-led interventions can reduce catheterisations by 42% and CAUTI by 57%.

Work is currently being undertaken by the Head of Community Nursing and North Lincolnshire Clinical Commissioning Group (NLCCG) to reduce avoidable admissions into hospital from care homes. The top primary diagnosis for admissions from care homes into hospital is UTI.

Gynaecology and pregnancy related continence issues

For many women, UI is linked directly to pregnancy and childbirth. Most women will either experience no symptoms or they will recover naturally, but for a significant number, symptoms persist, often for many years. All women receive post-natal advice from midwives, plus a leaflet on pelvic floor exercises. After birth, most women expect some minor continence issues, but health visitors will play a key role in discussing more persistent problems with women after the birth and referring as appropriate.

Females requiring gynaecological treatment may also present with a continence issue. Good working links do exist with urology, but there is currently no dedicated clinic or practitioner with an interest in continence related issues working in gynaecology. Pathways to physiotherapy and the specialist continence service are not in place.

Bedwetting (enuresis)

Many children experience problems with bedwetting. The majority will outgrow this problem by around age 5-6, and by age 10, the condition will only affect 1 in 20. However, for children who do wet or soil the bed, this can lead to significant distress. All children and young people referred into the continence service receive an initial assessment, and are discharged within a maximum of six months. Clear assessment and treatment pathways are in place.

Discussion — a new approach?

It is apparent that continence services is the archetypal 'Cinderella Service' and is a subject that is ripe for review. There has been no robust assessment of need since April 2001 (which focussed across North and North East Lincolnshire, and which used North Lincolnshire data from 1998), and local commissioning tends to be on the basis of historic usage, referral and treatment. It is not clear what changes to commissioning activity took place following this 2001 assessment.

The panel believes that, as the allocated budget in North Lincolnshire is so limited, and the workloads so high, preventative work by the specialist practitioners is strictly limited to where they can have the most impact. Increasing waiting lists seem inevitable under this model, with associated lack of dignity or financial hardship, and the risk of a range of medical conditions such as pressure ulcers. Studies have also found that incontinence is the second most common reason why older people move into care homes, when they may be able to continue living in their own homes with the appropriate treatment and support. As stated previously, UTIs and other related conditions also regularly result in avoidable admission to hospital.

Treatments for urinary incontinence are generally effective, and low-cost. Pelvic floor muscle training has a cure rate of up to 64% for stress urinary incontinence, minimally invasive surgical treatments (tension-free vaginal tape) have a 95% cure rate, and antimuscarinic drugs are proven to be cost-effective in 90% of cases of overactive bladder, through improved life quality and reduced pad costs. Low cost, conservative interventions delivered by a continence nurse specialist can cut pad usage by 50%, even in frail older people.

The panel believes that North Lincolnshire CCG should ensure the focus is firmly on preventative services, such as working with care homes, or increased use of pelvic floor muscle training, or low cost interventions. Studies have found that such interventions have a cost / benefit ratio "significantly below the level usually considered to be affordable in the NHS". Costs can be reduced further by running group sessions, where appropriate.

A preventative approach was identified in the 2001 Needs Assessment as the best method of meeting both current, unmet and future need, stating "An up-stream, preventative approach could break into the cycle of rising demand from an ageing population." The

assessment formally recommended that "In order to reduce the potentially increasing numbers of people likely to need continence services in the future, a preventive strategy should be developed. Those practitioners who are best placed to promote preventive action (midwives, health visitors, school nurses, for example), need to be aware of the role they can play".

There is evidence that admissions to hospital and care homes can be reduced through greater focus on prevention and community based support. For example, NICE guidance states that "it is estimated that establishing a paediatric continence service for children and young people aged 19 years and under could lead to a significant reduction in the number of admissions to secondary care for idiopathic constipation, by providing assessment and management of continence problems in primary and community settings. There is also the potential to reduce costs further by reducing the demand for continence products such as nappies or pads".

The All Party Parliamentary Group for Continence Care has highlighted a range of high-impact actions that will also deliver cost savings that could be reinvested in the service. These include effective and consistent catheterisation policies to prevent CAUTI, taking preventative action around pressure ulcers, proactive treatment of people with recurring continence issues to prevent admissions, and treating continence issues to prevent admission to a care home.

CONCLUSIONS

The striking impression that the panel received when looking at this issue was that this is a service that requires more attention. The services delivered appear very effective and delivered by skilled and empathic professionals. However, it has operated for many years on a very limited budget and with little attention beyond the practitioners and their managers.

The 2001 Needs Assessment identified a host of positive recommendations to improve services, but we have seen little evidence that actions were ever taken by the former organisations who commissioned the services. We are encouraged that North Lincolnshire Clinical Commissioning Group appears more positive about improving the service.

We feel strongly that there are some relatively easy steps that can be taken to improve the service, which also have the potential to save money. In turn, this can be re-invested in the service, ensuring that the budget is used as effectively as possible and that the care provided is clinically appropriate and effective. Highlighting the historic and nationwide lack of attention on continence services, the Continence Care Services 2013 survey states that "there is a danger that [continence] services will become simply a 'pad service' and the skills to deliver complex treatment and management options will be lost." We believe that, with a little thought, co-operation and attention, this danger can be avoided within North Lincolnshire.

This will certainly be a challenge, but we are confident that each of the partners who will play a key role in making the necessary improvements to services recognise the profound and far-reaching impact that continence issues have on many thousands of North Lincolnshire residents.

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